



**THE SON-RISE PROGRAM  
INTERVENTION FOR AUTISM: AN  
INVESTIGATION INTO PREREQUISITES  
FOR EVALUATION AND FAMILY  
EXPERIENCES**

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# ABSTRACT OF THESIS

This thesis examines parental involvement in interventions for autism, focusing specifically on the Son-Rise Program (SRP), a 1:1 American therapy run by parents in their own home. The research is set in context through a review of the literature on theories of autism and family systems theory, and a discussion of how these relate to research on intervention. Two themes are developed which are dealt with throughout the thesis: the effects of intervention involvement on the family as a whole and issues surrounding evaluation of the efficacy of interventions. These themes are explored through a series of five interlinking studies, in which both quantitative and qualitative methodologies are utilised.

The first study surveyed changes over time in the types of non-school based interventions used with children with autism within one Scottish region and variation in degree of parental involvement. Findings showed that there had been an increase in parental involvement in interventions over recent years, and in particular an increase in the uptake of the SRP. The remaining four studies focused in detail on this particular intervention. Study 2 explored some of the issues surrounding intervention evaluations, and specifically the notion that the validity of evaluations may be compromised if the evaluation research is designed in a way which is unrepresentative of how the intervention is used outwith the research environment. This difficulty can only be avoided if a study profiling typical users and typical patterns of use has first been undertaken. Study 2, a one-year repeated measures questionnaire survey of 90 parents trained in the use of the SRP, attempted to do this. It also aimed to describe the experience of being involved in the SRP from the perspective of the families implementing it, exploring issues such as effects on siblings, family stress, and financial implications. Study 3, a one-year repeated measures interview study of 6 parents, explored some of the issues raised in greater depth.

Studies 2 and 3 found a heterogeneous group of children involved in the SRP and a wide range of ways in which the program was being adapted by parents to suit their own child and family circumstances. This led to consideration of another threat to the validity and reliability of evaluation research, that of 'therapist drift' - when therapists drift away from the correct implementation of intervention techniques over time (Jordan & Powell, 1996). Study 4 explored therapist drift through a longitudinal video analysis study of 6 mother-child pairs involved in the SRP. Videos were analysed for changes in the mother's techniques which might be indicative of therapist drift, and also for changes in the child's behaviour which might have been related to these. In study 5 the mothers who had participated in the previous study were interviewed to explore further their experience of implementing the Son-Rise techniques over the course of a year. Results from studies 4 and 5 showed patterns which may have been indicative of therapist drift in some of the families. Possible explanations for this, as well as the influence of training on therapist drift were considered. The findings of all 5 studies are drawn together and implications for families considering a SRP, as well as for professionals advising these families, are discussed. The relation between the findings and relevant autism and family theories are also considered.



## **DECLARATION**

This thesis has been composed by me and is entirely my own work. Publications arising from this thesis are included in the appendices. The joint author and the publishers of these publications have granted permission for this inclusion.

Katie Williams

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## LIST OF ABBREVIATIONS

SRP	Son-Rise Program
3Es	Energy, excitement, and enthusiasm
PEACH	Parents for the Early Intervention of Autism in Children
TEACCH	Treatment and Education of Autistic and Related Communication-Handicapped Children
BPS	British Psychological Society

# CHAPTER 1

## UNDERSTANDING AUTISM: IMPLICATIONS FOR INTERVENTION

### 1.1 Introduction

This thesis examines the use by UK families of the Son-Rise Program<sup>1</sup>, an intensive home-based intervention for children with autism, which originated in the United States (Kaufman, 1976). The Son-Rise Program (SRP) is one of an increasing number of interventions that involve the parents in a therapeutic role. Yet, despite this growth in parental involvement, previous research into interventions for autism has tended to consider the child in isolation, rather than as part of a whole family system, with many issues relating to the parents and siblings remaining largely unexplored. Even such rudimentary facts as how common it is for parents to take on the role of their child's therapist are unknown. This will be addressed within this thesis as will family issues relating specifically to the SRP including the effects on the whole family of being involved in this type of intensive intervention and the ways in which parents adapt the Program to suit their own child and family circumstances.

A second theme to be explored in this thesis relates to the evaluation of autism interventions. Although there is a real need for rigorous evaluations of interventions such as the SRP, too often these are undertaken before adequate groundwork has been carried out to examine how the intervention tends to be used by families. For example, it is rarely established which type of children the intervention is being used with, how intensively it is used, whether it is used in conjunction with other interventions, and whether parents implement the techniques as they have been taught. As a result there are often no guarantees that intervention evaluations reflect how an intervention is used by families in the 'real world'. Ultimately this may make it difficult for families to make an informed decision on which intervention is most suitable for them and their child.

Before investigating these particular areas of interest, the aim of autism interventions in general and of the SRP in particular must be considered. This requires discussion of the key

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<sup>1</sup> The Son-Rise Program is a registered trademark.

developmental difficulties associated with the syndrome and consideration of how neurobiological and psychological development in autism differs from typical child development. The ways in which the features of autism affect the family of the child with autism must also be considered.

## **1.2 The diagnostic criteria**

Broadly defined, autism is a neurological disorder with symptoms forming a 'triad of impairments', with difficulties shown in communication, in social interaction, and in imaginative play (Wing & Gould, 1979). Restricted, repetitive patterns of behaviour form another part of the diagnostic criteria. While learning disabilities are not part of the diagnostic criteria they are a common additional feature, found in 75% of people with autism (Bryson, Clark & Smith, 1988; Lotter, 1966; Wing & Gould, 1979). Kanner (1943) first described autism as a "biologically provided disturbance of affective contact". Currently it is viewed as one category within a whole spectrum of social-communication disorders which includes Asperger syndrome, atypical autism, and autistic traits (Gillberg, 1996). A number of additional syndromes are also considered to be part of this 'autistic spectrum', but those listed above are the ones most relevant to the studies carried out within this thesis and will therefore be described in this chapter. For a description of other syndromes within the spectrum see Wing 1996a and Trevarthen *et al*, 1998.

Autism is usually diagnosed at around 5 years of age using one of two diagnostic systems – the World Health Organisation's International Classification of Diseases (ICD) and the American Psychiatric Association's Diagnostic and Statistical Manual (DSM). Both systems incorporate the triad of impairments, described in more detail below.

### **1.2.1 Communication impairment**

Communication in many children with autism develops normally for the first year of life, but by the second year there may be clear signs of impairment in the prelinguistic forms of social communication. Two of the first notable signs are that the infant may not use protodeclarative pointing, that is pointing to items of interest, or make use of joint attention by attempting to attract the caregiver's attention to objects and events by pointing combined with eye contact (Baron-Cohen, 1989a). Both of these important skills normally emerge at around 9-14 months. Social referencing, that is looking at the caregiver's face for clarification in an ambiguous or

mildly threatening situation, also normally emerges around this time, and is another skill that children with autism are less likely to develop (Sigman & Kasari, 1995).

Impairment in verbal communication, however, often provides the first cause for concern in parents of children with autism (Howlin & Moore, 1997). Some children begin to develop speech as normal but then cease to progress and may lose their existing vocabulary (Volkmar & Cohen, 1989). Other children are delayed in the acquisition of language and many fail to develop functional speech.

Even for those children who do develop language there may still be a number of difficulties. For example, approximately 80% of people with autism who do have speech are echolalic, that is they repeat back, verbatim, what others have said. Speech may also be monotonous, staccato or mechanical in quality (Howlin, 1998a). Other difficulties include pronoun reversal, over literal interpretation of language, and difficulty in understanding jokes, sarcasm, irony and metaphor. In particular the difficulty lies in the social use of language (Wing & Attwood, 1987). For example, children may use language to obtain objects but use it much less frequently to gain or share attention. For others, the social conventions surrounding conversation may be problematic, such as turn taking, making eye contact to signal turn taking, and avoidance of inappropriate topics.

### **1.2.2 Social impairment**

By the second year of life children with autism may already show signs of impairment in their social development and interactions. However, the image of children with autism as totally withdrawn and socially unresponsive is not entirely accurate (Mundy & Sigman, 1989). In fact many children with autism show a normal secure attachment relationship with their primary caregiver (Capps, Sigman & Mundy, 1994).

Wing and Gould (1979) emphasise that, although all children with autism show social impairment, the extent of this varies greatly. They suggest that children can generally be assigned to one of three categories based on their predominant behaviour. Those in the 'aloof' group are largely isolated and unresponsive. They make little eye contact and tend to avoid physical contact, although may enjoy rough and tumble or tickling games which require little

verbal interaction. Children in the 'passive' group are more likely to accept social approaches but are unlikely to initiate them. Again, eye contact is poor, but may be established through prompting. The 'active but odd' group are more cognitively and linguistically able and will make social initiations to others, but have difficulties with the social norms of interaction. For example, they may approach strangers and show inappropriate displays of affection. They may talk excessively about a particular interest and their gesture, facial expression and eye contact may be exaggerated and inappropriate. A fourth group, 'over formal, stilted', was added by Wing (1996a) to describe behaviour sometimes seen in early adulthood, again in those who are more cognitively able. This group is excessively formal and tend to treat family members as though they were strangers. They often stick rigidly to the rules of interaction, even in situations where more flexibility is required.

Although there is variation in the extent of social impairment, and how this is expressed, at all levels there is an inability to fully understand other people's feelings, beliefs and emotions, an impairment described as 'mindblindness' (Baron-Cohen, 1995). While children with autism do not have an absence of emotional response themselves, their difficulty lies in understanding the emotions of others (Hobson, 1986; Sigman & Capps, 1997).

### **1.2.3 Impairment in imagination and play**

Imagination and play are also adversely affected in the child with autism. Some children display age-inappropriate toy play such as sniffing or stroking objects. They may also manipulate certain parts of an object repeatedly or line objects up in rows. Obsessive attachment to toys or unusual objects is also very common.

Pretend play, a skill that normally emerges between 12 and 24 months, does develop in some children with autism, but often remains at the initial stage of functional play, e.g. pretending to drink tea from a toy cup. They rarely engage in sophisticated forms of pretence, such as imagining objects that do not exist, imbuing objects with properties, or attributing emotions, desires and beliefs to pretend characters (Baron-Cohen, 1987; Libby *et al*, 1998).

More able children may appear to engage in elaborate pretend play, but this is often repetitive and may be copied from television or books, rather than being truly inventive. They are also

unlikely to use imaginative skills in a social context, by joining in the imaginative games of other children.

#### **1.2.4 Restricted repertoire of activities and interests**

One of the most salient aspects of behaviour in children with autism is the restriction they often show in activities and interests. Simple, stereotyped repetitive behaviours such as hand flapping, rocking, and spinning objects often occur in younger children. Such behaviours may continue into adult life, especially in those with learning difficulties.

More elaborate activities include rigid arrangement of possessions, fastidious adherence to routines, and extensive repetition of activities such as watching videos and reading books. There may be very strong resistance to change with children becoming extremely distressed if their routine is altered in even a relatively minor way. In more able children there may be an obsession with a particular topic, with the obsession sometimes continuing into adulthood.

#### **1.2.5 Additional features**

There are a number of additional behaviours that are seen in some children with autism but are not universal and do not form part of the diagnostic criteria. These include abnormalities of gait, idiosyncratic responses to sensory stimuli and savant skills.

In addition to the behavioural symptoms, around a quarter of individuals with autism have an underlying medical disorder such as tuberous sclerosis or fragile-X syndrome (Gillberg & Coleman, 1996). Around a fifth develop epilepsy, with the likelihood of this increasing in those with profound learning difficulties (Bailey, Philips & Rutter, 1996).

#### **1.2.6 Changes with maturation**

Although autism is a lifelong disability the presentation of symptoms is likely to change as the child matures. For example, there is a trend for 'aloof' children to display 'passive' or 'active but odd' characteristics as adults (Wing & Attwood, 1987). In some children who have shown marked autistic symptomology in the early years the behaviour becomes less obvious at around 6 years. Adolescence may, for some, be another time of change, with inappropriate behaviour becoming more marked (Wing, 1996a, 1997a).



### **1.3 Other groups within the autistic spectrum**

Children and adults diagnosed with an autistic spectrum disorder will show some or all of the triad of impairments described above in relation to autism. However, within the autistic spectrum there is great variation in the severity of these symptoms. Those with Asperger syndrome share the social and communication difficulties that characterise 'typical' autism, but symptoms are less severe and there are no accompanying learning difficulties. In terms of social impairment a child with Asperger syndrome will not be withdrawn and may indeed actively elicit social interaction, but will lack the appropriate skills such as turn-taking to maintain a successful exchange. Linguistic deficits too may be relatively subtle, taking the form of fluent speech that is rather pedantic and monotonous. Like autism, those with Asperger syndrome will usually have all-absorbing interests and routines. Trevarthen *et al* (1998) note that clumsiness and a lack of appreciation for humour are also commonly described as features.

Another group recognised within the spectrum is atypical autism, in which onset is after 3 years of age and difficulties are in only one or two of the triad of impairments. Other diagnostic labels include autistic traits, tendencies, or features. These diagnoses are often used when symptoms are less severe, or co-occur with other difficulties.

### **1.4 Age of diagnosis**

Parents often become anxious about their child's development when their child is as young as 18 months. The majority of children with autism are diagnosed before the age of 5 years, many as early as 3 years, although children with Asperger syndrome are likely to be diagnosed later (Howlin & Moore, 1997). There is also considerable regional variation in age of diagnosis throughout the UK, with families in more densely populated areas and near specialist services obtaining a diagnosis earlier (*ibid*).

The age at which children are diagnosed has decreased over recent years (Howlin & Moore, 1997; Smith, Chung & Vostanis, 1994). This trend is likely to continue with the introduction of the Checklist for Autism in Toddlers (CHAT), a screening questionnaire completed by the health visitor or GP for children aged 18 months. It is based on some of the key impairments described above, such as joint attention, protodeclarative pointing and pretend play which, if absent at 18

months, may suggest the presence of a social-communication disorder (Baron-Cohen, Allen & Gillberg, 1992; Swettenham, 1996). In the future even earlier screening may be possible, based on levels of neuropeptides and neurotrophins in neonatal blood, but at this time such techniques cannot distinguish between autism and more general learning difficulties (Nelson *et al*, 2001).

## **1.5 Prevalence of autistic spectrum disorders**

Definitive information on prevalence rates for autistic spectrum disorders is difficult to establish. A number of studies found that autism had a prevalence rate of 4 to 5 per 10,000 (Lotter, 1966; Hoshino *et al*, 1982; Wing & Gould, 1979). Wing (1993) notes, however, that because these studies used Kanner's criteria - profound lack of affective contact and elaborate repetitive ritualistic behaviour - they may have underestimated prevalence since these rule out both the most severely learning disabled children, who might not be capable of elaborate repetitive routines, and the more able children, who tend to make more social approaches.

Using wider criteria based on the triad of impairment, but excluding Asperger syndrome, prevalence rates from 7 to 22 per 10,000 have been found (Bryson *et al*, 1988; Steffenberg & Gillberg, 1986; Wing & Gould, 1979). For Asperger syndrome rates from 10 to 36 per 10,000 have been reported (Ehlers & Gillberg, 1993; Gillberg & Gillberg, 1989). Wing (1993) concludes that the combination prevalence figure for all children with autistic spectrum disorders may therefore be 47 per 10,000. More recent reports have suggested it may be as high as 91 per 10,000 (Wing, 1996b), although such prevalence estimates must be treated cautiously as they are based on extrapolation and there may also be overlap between the groups that are combined to produce these figures (Howlin, 1998a).

The number of childhood diagnoses of autism has increased over recent years, although there is still an under-identification of children based on the expected numbers calculated from prevalence rates (Jordan & Jones, 1996). The increase in diagnosis rates may be partly because medical and educational professionals who see children with developmental disorders have become more aware of autistic conditions (Wing, 1996b). Also, the definition of autism has widened, along with the recognition that it can co-occur with other disorders (Gillberg & Coleman, 1996; Wing, 1996b). Others have argued that an additional reason for the increase in diagnostic rate is that there are now a greater number of children developing autistic disorders,

perhaps due to adverse environmental factors, such as the introduction of organo-phosphorus pesticides (Shattock, 1999). The combination MMR vaccine has also been put forward as another modern causal factor, as has the high level of mercury contained in other infant vaccines, although these remain highly contentious hypotheses (Bernard *et al*, 2001; Wakefield *et al*, 2000; The Committee on Safety of Medicines & Medicines Control Agency, 2001). Either way, consistency of methodology and diagnostic criteria across studies is required before any comparisons of prevalence rates over time can be truly validated (Wing, 1993).

Most studies report gender ratios of around four males to one female, although ratios as high as 13:1 and 16:1 have been noted (Gillberg, Steffenburg & Schaumann, 1991; Wing & Gould, 1979; Wing, 1993). Gender ratios also vary depending on whether learning difficulties are present in addition to the autism. Lord, Schopler & Revicki (1982) found a male:female ratio of 5:1 at the higher end of the IQ range and only 3:1 at the lower end. Others have found similar ratios (Wing, 1981). Trevarthen *et al* (1988), however, note that Rett syndrome, a mental handicap that affects primarily girls, was not identified as being distinct from autism in the 1980s. Had it been taken into account in these studies, the male:female ratio would in all likelihood rise in the lower IQ group.

Although early studies found an over-representation of autism in higher social classes (Lotter, 1966) more recent work has not found such an association (Gillberg, 1984; Wing, 1980). Wing (1996a) concluded that while autism is not more prevalent in higher social classes in real terms, there might be a higher rate of diagnosis as a result of greater financial means to travel to specialists as well as the personal/financial resources to obtain information on autism. Frith (1989) suggested that in addition to referral bias, it might be the case that in higher social classes autism is less likely to co-occur with learning difficulties, making it easier to diagnose.

## **1.6 Theories of autism**

Understanding autism at a behavioural level is of clear importance, but there is also a need that this be linked to relevant theoretical work. Happe (1994) notes the importance of considering three levels of explanation - behavioural, neurobiological and psychological - if a more holistic understanding of autism is to be achieved.

### 1.6.1 Neurobiological theories of autism

Findings that around a fifth of individuals with autism develop epilepsy suggest that there is some form of brain dysfunction in autism (Bailey *et al*, 1996). However, pinpointing specific areas of damage is problematic, in part due to the difficulty of unravelling which neurological abnormalities are associated with autism and which with commonly co-occurring conditions such as epilepsy and learning difficulties (Happe, 1994). In addition the possibility remains that medication or even 'autistic behaviour' may have an effect on brain tissue, making conclusions about the causal role of neurological impairment particularly difficult to establish (*ibid*).

Despite these difficulties there have been numerous studies that have attempted to identify key neurological features of autism. Several have shown the cerebellum to be malformed. Courchesne *et al* (1988) reported a lack of development in the mid portion of the cerebellum in a large number of adults with autism, both with and without additional learning disabilities, which led to a model of autism based on cerebellar abnormalities (Courchesne, 1989). However, the argument that cerebellar abnormalities are the most consistent neuroanatomical lesion in autism is not without contention; others have failed to find any abnormalities in this region (Garber & Ritvo, 1992; Kleinman, Neff & Rosman, 1992), and there have been reports of similar cerebellar malformation in cases without autism, indicating that such damage may not be specific to autism (Schaefer *et al*, 1996). Trevarthen *et al* (1998) suggested that abnormal development of the cerebellum might be more usefully viewed as an indicator of the probable timing of developmental problems in autism rather than as a physical feature that can identify the clinical disorder.

Further sites of neurological impairment which have been proposed include purkinje cells and the limbic system. Purkinje cells, which are found in the cerebellum and are the source of connective fibres leading to other regions of the brain, are reduced in number in cases of autism (Bauman & Kemper, 1994; Ritvo *et al*, 1986). However, Bailey *et al* (1996) note that because purkinje cell loss is a recognised complication of epilepsy, and some of the individuals in these studies did have a history of epilepsy, it is difficult to pinpoint this as a deficit specific to autism. The limbic system is an area responsible for emotional regulation, memory and learning. Kemper and Bauman (1993) found that cells in this region were smaller in size and more densely packed in cases of autism.

In terms of neurochemical research, serotonin – a chemical involved in sensory perception, motor functioning, learning and memory – has been implicated in autism. Cook (1990) reviewed studies in this area and found consistent reports of significant blood serotonin elevation in about 30% of individuals with autism. Studies of other neurochemicals have failed to produce any consistent evidence of abnormality in individuals with autism, however (Bailey *et al*, 1996).

There is strong evidence of a genetic link in autism. Indeed it may be the most strongly genetic of all multifactorial psychiatric disorders (Rutter *et al*, 1993). Folstein and Rutter (1977) studied 21 twin pairs (11 identical, 10 fraternal) in which at least one of each pair had a diagnosis of autism. There was concordance for autism in 4 out of the 11 identical pairs and in none of the fraternal pairs, strong evidence for a genetic cause. This finding has since been replicated (Bailey *et al*, 1995; Ritvo *et al*, 1985; Steffenberg *et al*, 1989). While evidence for the genetic transmission of autism exists, Bristol *et al* (1996) and Tsai (1999) note that it is highly unlikely that any single gene change can account for such a complex disorder of brain development and, if autism is heritable, that several different genes will probably be implicated. To date genetic loci on almost all the chromosomes have been implicated, although anomalies involving chromosome 15 are the most frequently reported (Elder, 2000; Gillberg, 1998).

The rate of autism in siblings is between 3 and 7%, far higher than the rate in the rest of the population (Piven *et al*, 1990; Jorde *et al*, 1991). It has also been found that siblings of individuals with autism have higher than chance rates of intellectual impairment and communication problems, suggesting genetic transmission for a more general disorder of social and cognitive development, perhaps with autism as just one of its manifestations (Folstein & Rutter, 1977; Le Couter *et al*, 1996; Piven *et al*, 1990).

While neurobiological research has not yet identified key features which are both specific to autism and universal across all cases, there have then been regions of the brain identified which seem likely to be involved in the development of the syndrome to some extent. However, attempts to produce causal models linking these to key symptoms and psychological theories of autism have, to date, been limited. It seems likely that functional brain imaging techniques offer the greatest potential in the future for integrating these different levels of explanation (Bailey *et al*, 1996).

### 1.6.2 Psychological theories of autism

While there has been much neurobiological work in autism in recent years, this has been somewhat overshadowed by the explosion of psychological research. One of the most influential current psychological theories of autism is 'theory of mind'. This is hypothesised to be an innate cognitive 'module' that develops in the second year of life and allows the child to attribute mental states to others, and to theorise about, predict and explain their behaviour. It has been suggested that this mechanism that is impaired in autism causing the triad of impairments (Baron-Cohen, Leslie, & Frith, 1985; Leslie, 1987).

A series of 'false belief' studies has provided some evidence for the 'theory of mind' deficit hypothesis. Through these it was shown that children with autism consistently fail to appreciate that another child could hold a different (false) belief from their own, thus illustrating their difficulty in attributing mental states to another person (Baron-Cohen *et al*, 1985; Perner *et al*, 1989).

Such 'mindblindness' (Baron-Cohen, 1995) could explain a number of the symptoms of autism. It would predict that only some social capacities would be impaired, i.e. those such as reciprocal social interaction and empathy which require a concept of other people's mental states, whereas social skills that do not require mentalising ability would be unaffected (Frith & Happe, 1994). There is much experimental evidence to support this prediction (Baron-Cohen, Leslie, & Frith, 1986; Baron-Cohen, 1989a; Sodian & Frith, 1992).

However, a number of more recent studies have demonstrated that a lack of theory of mind is neither specific to autism, nor universal across all cases. Some deaf children and children with Down syndrome also fail false belief tasks (Peterson & Siegal, 1995; Zelazo *et al*, 1996). Some children on the autistic spectrum can pass the false belief tasks, and can also succeed on second order theory of mind tasks which involve thinking about another person's belief about what a third person believes (Bowler, 1992; Happe, 1993). High-functioning people with autism do though show more subtle theory of mind deficits, such as an impairment in the ability to infer the mental state of a person from a photograph of their eyes and a difficulty in recognising faux pas (Baron-Cohen, Jolliffe, *et al*, 1997; Baron-Cohen *et al*, 1999). Baron-Cohen (1989b) concluded that the theory of mind impairment in autism might represent a delay rather than a deficit.

Trevarthen *et al* (1998) point out that tests of theory of mind can only be used with individuals who have relatively good verbal skills and thus the theory can only be applied to high functioning children with autism. They also note that the theory of mind impairment is only one “facet of a disorder which begins to affect the human mind at a far more fundamental level”, and suggests that autism results from much deeper and earlier disturbances in intersubjective functioning, the ability to perceive and connect with other people’s mental states through their affective-expressive behaviour. This view is echoed by other authors (Fein *et al*, 1986; Klin, Volkmar, & Sparrow, 1992).

Hobson (1993) also believes that difficulties lie at a more fundamental social level, and criticises the theory of mind approach for failing to acknowledge the influence of social interaction on the development of mentalising abilities. In typically developing children innate capacities for ‘interpersonal relatedness’ lead to reciprocal interactions that allow the child to come to know that people have minds (Hobson, 1991). Hobson believes that, in contrast, there is a primary deficit in children with autism in the ability to engage in such intersubjective interaction.

Hobson’s affective-deficit theory is supported by the evidence that children with autism are impaired in matching facial expressions of emotion with corresponding gestures and vocalisations (Hobson, 1986). Children with autism are also more likely to sort pictures of people by their clothing than their emotional expressions, unlike typically developing children, again suggesting that people’s emotions may not be as salient to children with autism as they are to other children (Weeks & Hobson, 1987).

Other theories have focused more on cognitive than social abilities. Frith (1989) has proposed that an impairment in central cohesion, the mental process from which we derive higher level meaning by weaving together otherwise piecemeal information, may be part of the problem which underlies autism, and there is a body of experimental evidence to support this theory. For example, people with autism are poor at recognising the contextually appropriate meaning of everyday homographs (e.g. son-sun, meet-meat), as they do not examine the meaning of the individual words as part of the overall meaning of the whole sentence (Happe, 1997). They do, however, show superior ability on block design and embedded figure tasks, possibly because



they look at the individual pieces of information in the picture and are not overwhelmed by the 'predominance of the whole', as are typically developing children (Shah & Frith, 1983, 1993).

Central cohesion theory can explain a number of features of autism which theory of mind cannot (Frith & Happe, 1994). For example impairment in central cohesion could explain savant skills such as the ability to produce complex architectural drawings, a process better solved by piecemeal information processing than a more global approach (Frith & Happe, 1994). Echolalia may also reflect the child with autism processing only a few words of the sentence, rather than the whole, and hence being unable to respond appropriately. The possibility of course remains that central cohesion and the theory of mind approach could be merged to produce a more holistic and unified explanation of autism (Bailey *et al*, 1996).

Executive function theory suggests another cognitive impairment that could co-exist with theory of mind difficulties. Executive function is an umbrella term that covers a range of behaviours necessary to attain a goal. These include planning, inhibition of irrelevant responses and flexibility of response, operations typically associated with the frontal lobes (Ozonoff, Pennington, & Rogers, 1991). Hughes, Russell & Robbins (1994) have demonstrated that children with autism have difficulty in the domains of planning and cognitive flexibility when faced with tasks requiring executive functioning, a finding since replicated in numerous studies (reviewed in Pennington & Ozonoff, 1996).

Hughes and Russell (1993) propose that children's failure on some theory of mind tasks could equally well be explained by an impairment in executive function, as opposed to difficulties in mentalising ability. Ozonoff *et al* (1991) suggest that executive function is the primary deficit, resulting in difficulties with theory of mind, although also consider the possibility that a third deficit is causing both theory of mind difficulties and executive impairment.

While the theories outlined above focus primarily on either cognitive or affective deficits, the theoretical perspective of Sigman and Capps (1997) combines the two. They approach autism from the perspective of developmental psychopathology – the notion that typical and atypical development can be understood clearly only when the two perspectives are combined. They suggest that, given that cognitive and emotional development is inextricably linked in typically

developing children, a workable theory of autism must also consider both types of deficits together. Sigman and Capps suggest that there are 4 precursors to social understanding in typically developing children:

- (1) children attend and react emotionally to social and nonsocial events
- (2) they become aware of their reactions
- (3) they seek out and interpret others' vocal, facial and behavioural displays of affect
- (4) they match and compare their own reactions with those of other people.

Sigman and Capps believe that these precursors are the foundation for understanding that others' perceptions, desires and beliefs are distinct from our own and for interpreting our own and others' emotions and actions within the context of cultural norms, expectations and conventions. They note that existing research makes it difficult to pinpoint precisely the scope of autistic impairment in any of the four areas outlined above. However, they feel that the impairment must stem from deficits in both cognitive and affective areas, on the grounds that children with autism experience the most difficulty in situations that require integration of these two areas – the type of situations in which typically developing children acquire the foundation for ongoing participation in social relationships. Such situations include those which involve pretend play, joint attention and social referencing –all of which combine both an affective and a cognitive component.

There is then a strong body of evidence supporting each of these psychological explanations of autism, particularly in relation to theory of mind. More recently, research in this area has drawn on the evidence of a substantial genetic component in autism, and has begun to explore the possibility of a “broader autism phenotype” in the parents and siblings of those diagnosed with autism (Baron-Cohen, Bolton *et al*, 1997; Briskman, Happe, & Frith, 2001; Happe, Briskman, & Frith, 2001). A challenge for the future is to demonstrate conclusively how these various theories of autism relate to each other, if at all (Bailey *et al*, 1996; Frith, 2000).

## 1. 7 The family experience of autism

In addition to developing an understanding of the behavioural, neurobiological and psychological mechanisms operating in autism, it is necessary to view the child within the context of the family, if we are to fully comprehend the practical implications of the resulting syndrome.

The diagnosis of a child's developmental disorder is a difficult time for any family, but in the case of autism it may be particularly stressful because it cannot be diagnosed at birth; instead, there is a growing awareness and fear that something is wrong (Cutler & Kozloff, 1987). Parents' reactions to diagnosis may include depression, guilt and anger, and some may begin to question their own competence as a parent (Cutler & Kozloff, 1987; DeMyer, 1979). Others find that diagnosis comes as a relief; finally having a label for the child's behaviour can provide reassurance, and is the first step towards finding appropriate education and support (Tissot, 1999). For some families the diagnostic procedure is made more distressing by lengthy delays and sometimes the lack of an unequivocal diagnostic label at the end of this process (Dunlop & Laws, 1997; Howlin & Moore, 1997).

Following diagnosis the family must begin to come to terms with not only this but also with all the associated difficulties of trying to access information on appropriate educational provision, benefit entitlement, and support groups. Findings from a survey of nearly 1300 parents of children with autism showed that nearly a fifth were not offered any form of professional assistance with such issues following diagnosis (Howlin & Moore, 1997).

*"Parents looking for advice and information find they are often left to return home with their child feeling overwhelmed and helpless, with no practical assistance to help deal with everyday life and how to live with autism." (Dunlop & Laws, 1997)*

Living with a child with autism can be filled with positive experiences, but there is no doubt that there are also difficulties. Cutler and Kozloff (1987) note that stresses inherent in living with a child with autism may include dealing with a child who cannot communicate needs and wants, coping with inappropriate and ritualistic behaviour, and constantly monitoring a child who may not recognise dangers. This stress is often exacerbated by society's response to the child (Cutler

& Kozloff, 1987; Kozloff, 1984). In some families this stress will result in isolation, depression or marital breakdown. In others the experience of having a child with autism will bring the family closer and have an enhancing effect on family emotional strength (Akerley, 1984). In either case, support from wider family, friends, respite services and support groups is central to reducing the stress associated with living with a child with autism (Cohen, 1998; Sanders & Morgan, 1997).

For some families autism becomes the “axis around which the family revolves” (Cohen, 1998), and parents may worry that they are not giving enough time to the other children in the family in their efforts to meet the needs of the child with autism (Akerley, 1984; Cutler & Kozloff, 1987; Holmes *et al*, 1982). In reality though, parents often strive to meet the needs of the other children and the needs that are least likely to be met are the personal needs of the parents, leading potentially to physical and emotional exhaustion (Cutler & Kozloff, 1987; Marcus, 1984).

Siblings too are likely to be affected. For some children the responsibility of having a sibling with autism will have a positive outcome, resulting in greater maturity, altruism, and improved tolerance, but others will be adversely affected, particularly if they have excessive responsibility for the child with autism (Harris & Powers, 1984; McHale, Simmonsson, & Sloan, 1984).

The pattern of stress and family functioning is not likely to be static, but will vary over time. Families with an older child with autism suffer more stress than those with a younger child (Bristol, 1979). This may seem at odds with the fact that children tend to show some improvement in symptoms as they age, but it may be that parents are mentally prepared for the fact that a younger child will have sleepless nights and require close attention and time for childcare (Harris & Powers, 1984). Parents may also cope better when the child is younger because society is likely to be more tolerant of non-typical behaviour in younger children. As time goes on, parents have to face the irreversibility of the disorder and may have to accept the role of perpetual caregiver when their child is an age at which typically developing children are becoming more independent (DeMyer, 1979; Marcus, 1984). Some parents also have concerns about what will happen to their child after they can no longer care for him or her (Kozloff, 1984).

It would be wrong to imply that living with a child with autism means constant difficulty and stress, although research has inevitably focused more on this than on the positive aspects. Living with a child with autism does though alter the family dynamic, which will continue to change over the course of the child's life. As living with a child with autism may, at some times, be a source of stress for the family it is important that if parents do take on interventions these do not significantly increase overall stress (Bristol, 1984).

## **1.8 Intervention approaches for children with autism**

Despite the fact that the precise aetiology and nature of autism remains something of an enigma, there has then been clear progress in attempts to describe the behavioural, neurobiological and psychological mechanisms involved in the disorder, as well as an acknowledgement of the need to understand the impact autism has on the whole family. Tying this knowledge into intervention research is essential if effective, rigorously evaluated approaches for treating autism are to be developed.

The central impairments in social interaction, verbal and nonverbal communication, imaginative play, along with the associated patterns of repetitive behaviour, are likely to be the main focus for any kind of intervention. Rogers (1999) emphasises that because there are several areas of impairment in autism, interventions should not be too narrowly focused as there is no evidence that addressing one area of deficit in autism will advance development in other areas. It is also clear that there is wide variation amongst children in the extent of the various impairments, and so for some children it is more appropriate for interventions to focus on early developmental skills such as eye contact and pointing, whereas for other children more sophisticated abilities such as conversational conventions should be addressed. This variation across the autistic spectrum suggests that no one single intervention would be suitable for all children with autism (Bristol *et al*, 1996).

The fact that symptoms are not static, but can change with maturation, also has implications for intervention. Firstly, it suggests that an intervention that was appropriate for a child at one age may not necessarily be appropriate for the same child when she/he is older. Secondly, in terms of intervention evaluation, it means that care must be taken not to assume that behavioural change is the result of intervention as it may simply be due to maturation.

In terms of rates of diagnosis, the number of children identified with autism each year has increased over time. Health and education services may well lack sufficient resources to meet this increased need and be unable to provide professional therapist-based interventions for all families. As a result, parents may increasingly turn towards interventions in which they themselves are the primary therapist. Similarly, because the mean age of children diagnosed with autism is decreasing, interventions for children of preschool age are also likely to become increasingly common. As preschool provision for children with autism has been identified as inadequate in some parts of the country (Jordan & Jones, 1996), use of parent-run home-based interventions may again be expected to rise, either in addition or as an alternative to professionally delivered interventions. Rogers (1999) notes that families may also be seeking out more intensive services than in the past, due to higher expectations shaped by the early intervention literature on the potential benefits of intervening at the earliest possible stage.

In terms of research into the neurobiological basis of the symptoms of autism, the fact that there has been no consistently reported lesion which is specific to autism and universal across all cases means that, to date, the ultimate goal of such research - to understand the pathophysiology of autism well enough to devise specific pharmacological intervention and prevention - has not been realised (Rapin & Katzman, 1998). Thus, for the foreseeable future, education and psychological interventions are likely to remain the most common methods of treating autistic symptoms. Neurobiological findings from typically developing children suggest that beginning such interventions when the child is young may be advantageous as neurological plasticity of function (the ability of the brain to compensate for loss of function) may decrease as the child ages (Bristol *et al*, 1996; Kolb & Wishaw, 1985; Niemann, 1996).

With respect to research into psychological theories of autism, Jordan, Libby, & Powell (1995) note that there is a distinct lack of literature connecting psychological theory with intervention methodology. One exception to this is the recent attempt to devise methods of training children in theory of mind tasks. These have met with some success, but there appears to be limited generalisation to new tasks or to everyday social competence (Ozonoff & Miller, 1995; Swettenham, 1995). Findings such as these suggest that teaching mentalising skills in isolation may not be effective and a more global approach to intervention may be necessary. This was noted by Trevarthen *et al* (1998) who also state their belief that interventions focused on intersubjectivity may be more beneficial:

*“It is a case of compensating for mis-steps in the intricate dance of rhythms and sympathetic signs that constitutes human communication. Autistic children need support and augmentation of their intersubjective awareness and skills...But mastery of such skills requires...more than training of discrete behaviours.”*

(Trevarthen et al, 1998:161)

Hobson's affective-deficit theory also seems to suggest a need for interventions to address this impairment in intersubjectivity by focusing on the interpersonal relationship between the therapist and child (Jordan *et al*, 1995). Interventions taking this kind of approach include Intensive Interaction (Hewett & Nind, 1989) and the Son-Rise Program (Kaufman, 1976). Each emphasises the importance of establishing, maintaining and developing reciprocal social interaction. They also promote socio-cognitive skills such as joint attention, suggested by Sigman and Capps' theory to be central to the child's later functioning. These interventions will be considered in some depth in Chapter 2 of this thesis.



## CHAPTER 2

# FAMILY INVOLVEMENT IN INTERVENTIONS FOR AUTISM

### 2.1 Introduction

In the previous chapter the effect on the family of living with an autistic child was discussed. One of the issues that this thesis examines is whether the family dynamic changes when parents run an intensive home-based intervention such as the Son-Rise Program. Some authors suggest that when parents take on the role of therapist in this way it exacerbates the existing pressures on the family. Others believe that involvement in interventions will lead to reduced stress and successful family adaptation.

In this chapter the history of parent involvement in interventions for autism will be discussed, as well as the role that family social development theory has played in the way the effects of this involvement are viewed. There is a complex pattern of potential effects when a family becomes involved in an intervention, and the chapter will be concluded by a review of a number of interventions for autism, and the research into the effects on families undertaking them.

Note that throughout this thesis, the term 'intervention' and 'therapy' will be used interchangeably to refer to any program of techniques that are used to try to change the child's behaviour. As a general rule interventions tend not to be used indefinitely with the child, but rather for a period ranging from a few months to several years. While the term 'treatment' will be used where necessary, this has more medical connotations and implies a cure as the endpoint, and so is avoided as far as possible (Selikowitz, 1997; Sigman & Capps, 1997).

### 2.2 History of parent involvement in interventions for autism

Prior to the 1960s parents of children with disabilities were rarely involved in the interventions used with their children. They were left largely unsupported and received few practical suggestions as to how they could help their child's development (Mittler & McConachie, 1983; Schopler & Mesibov, 1984; Wehman, 1998). This was especially so in the case of autism, as a result of the psychogenic theory of the disorder, which predominated in the 1950s (Wing, 1997b). This theory held that parents' lack of emotional warmth caused their child's autism, and

that the children should therefore be separated from their parents for treatment in institutions or foster homes (Bettelheim, 1967; Kanner & Eisenberg, 1956). Rather than being involved in interventions with their children, parents were often themselves viewed as patients and offered psychotherapy to remedy their 'emotional refrigeration' (Schopler, 1978).

A second phase in the role of parents in interventions for children with disabilities began in the late 1960s, with several studies involving parents as co-therapists in behavioural interventions (Berkowitz & Graziano, 1972; O'Dell, 1974). A number of factors contributed to increased parental involvement, in the case of autism the most notable being the recognition that parents' actions were not a causal factor. The psychogenic theory was found to be based on limited and anecdotal clinical observations which were refuted by the evidence from empirical studies (Cantwell, Baker, & Rutter, 1978; Wing 1966). These findings meant that parents were able to move away from the designated role of patient and become actively involved in their child's development, if they so chose.

Another factor contributing to parental involvement was the finding that gains made in behaviour modification programmes in clinics were retained if children were discharged to parents trained in behaviour modification techniques, whereas children sent to untrained parents in foster homes or institutions tended to regress. This finding suggested that training parents as co-therapists could be helpful in preventing a relapse in the child's behaviour (Lovaas *et al*, 1973).

It was subsequently recognised that there were a number of additional benefits of involving parents as therapists for their children with autism. The availability and intensity of intervention is increased, and it is economical, costing very much less than inpatient intervention (Hemsley *et al*, 1978; Howlin & Rutter, 1987; Koegel, Rincover, & Egel, 1982; Lovaas, 1978; Schopler *et al*, 1984; Zigler, 1984). It is also more efficient because it means that professional therapists are able to reach a much larger number of those in need of their skills, as they are involved in short-term training of parents, as opposed to more long-term direct work with the children (Clements, 1985; Harris, Wolchik, & Weitz, 1981). The number of months that the child is involved in intervention can also be increased, as unlike professional therapists, parents are not involved with their child's case for only a limited amount of time (Schopler *et al*, 1984).

The unique involvement a parent has with their child may also, in some ways, make them a more effective therapist than a professional worker. For example, they are likely to be highly motivated to persist with an intervention, and may be able to offer more individually tailored reinforcements for appropriate behaviour than outside therapists can (Howlin, 1984). As they are normally in a position of having more rapport with the child than a visiting therapist, they may be at a more advantageous starting point to carry out an intervention successfully. The child may show more advanced developmental skills when interacting with parents than with a therapist (Schopler & Reichler, 1971b), although this will probably depend on the level of training the parent receives. In terms of the progress of the child, it has also been noted that the involvement of parents can help children to generalise their skills to other environments as parents can use the therapeutic techniques on an informal basis outside the intervention sessions (Sheinkopf & Siegel, 1998).

A number of benefits of involving parents as therapists relate to the period after the intervention has ended. Parents may have gained the skills to prevent the development of problems that might otherwise occur at a later time, thus reducing the need for outside involvement by social and educational services. Parental involvement can therefore be viewed as a preventive service model (Berkowitz & Graziano, 1972; Clements, 1985; O'Dell, 1974; Schreibman *et al*, 1984). Also, parent involvement sometimes increases the parents' confidence in their ability to articulate their child's strengths and needs and they will thus be better equipped to deal with health and educational systems, resulting in a trend away from professional-dominated models of guidance seeking in later stages of the child's life (Cutler & Kozloff, 1987). It seems unlikely though that this will always be the case, and it will probably be determined by the extent to which parents were reliant on professionals for direction and advice during the time of their intervention involvement.

Over the past 40 years then, therapy with children with autism has moved from an institution/professional therapist based approach with little, if any, parental input to a realisation of the benefits of parent involvement in intervention delivery. Initially the literature in this area focused mainly on the effects on the child when parents took on a therapist role but more recently a wider view has been taken, which acknowledges that any intervention which involves

parents is likely to have an impact on the whole family, and that while parent involvement will benefit some families it will not be suitable for all (Telzrow, 1993).

This shift towards a family-centred view was influenced by the incorporation of family social development theory into the literature on early intervention for children with and without disabilities (Wehman, 1998). Relevant theoretical approaches include Minuchin's (1974) 'family-systems theory' and Bronfenbrenner's (1979) 'human ecology theory'.

Minuchin's 'family-systems theory' recognises that a family is more than a collection of individual family members: it is an interactional unit and factors which affect one member will often in turn affect the rest of the family. The family unit is therefore a constantly evolving dynamic system, adapting and restructuring itself over time in order to continue functioning effectively (Munice *et al*, 1995). A family system differentiates and carries out its functions through subsystems: individuals, dyads, or groups of family members formed by generation, gender, interest, or function.

According to family-systems theory parental involvement in intervention will inevitably influence the whole family. If, for example, one parent suffers stress as a result of involvement in a time-consuming intervention with their child, this will in turn affect how they interact with other members of the family, which may in turn influence how the rest of the family feel about the child with autism and the parent who has taken on the therapist role. The parent and child involved in the intervention will form a subsystem within the family, and the relationship between this subsystem and the rest of the family will be positive or negative depending on numerous factors, including whether the other family members feel excluded from the subsystem and the extent to which it affects the parent's involvement in their other family subsystems, e.g. time spent with spouse.

Bronfenbrenner's (1979) human ecology theory views the child as placed within a series of nested social systems: the microsystem level which the child directly experiences (such as family and peer group); the mesosystem level which links the various microsystems; the exosystem level (social structures which the child does not directly experience but which nonetheless affect him such as parents' employment and the local educational authority); and the

macrosystem level (the culture and tradition of the society in which the child develops) – see figure 2.1.

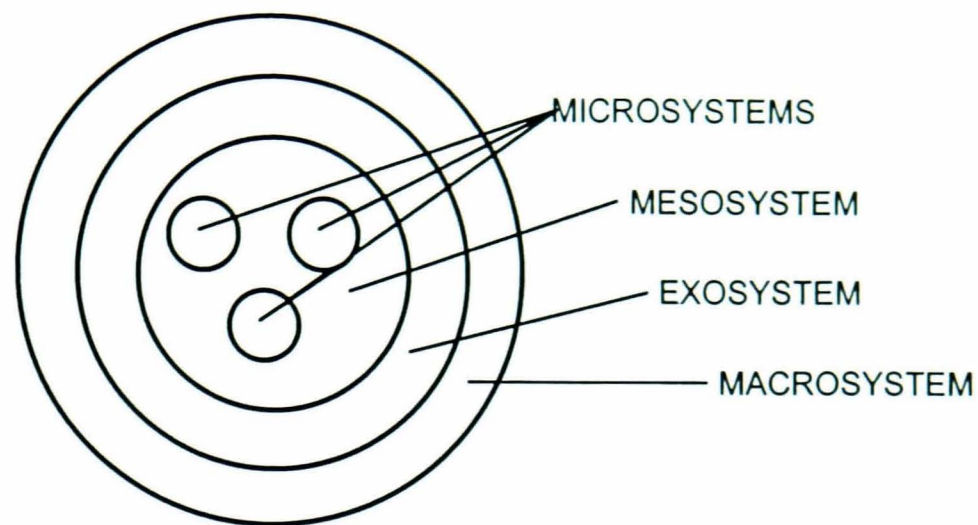


Figure 2.1: Bronfenbrenner's human ecology model

Components of this system interact with one another to influence the development of the child. This theoretical stance suggests that intervention involvement not only affects and is affected by the family unit, as Minuchin suggested, but that it must also be seen in the context of the wider community in which the family exists. For example, the decisions by the local education authority at the exosystem level regarding funding for interventions will affect the whole family's experience of that intervention at the microsystem level. Society's view of the role of parents in their child's education at the macrosystem level will similarly impact on the family microsystem level. From this theoretical perspective families cannot be viewed as functioning in isolation from society:

*"In the evolution of services to autistic children, a broader ecological family systems perspective is emerging which promises to facilitate child progress and maintenance of the child in the community while respecting the needs of the entire family in the social and cultural context of their community." (Bristol, 1985)*

As with family-systems theory, Bronfenbrenner (1986) notes that the family cannot be viewed as static, but as a constantly changing dynamic, as is the society within which the family exists. The family is therefore best studied thorough a 'chronosystem' model, that is, one which takes account of these changes over time.

Models such as those of Minuchin and Bronfenbrenner may appear somewhat limited in that there will often be situations in which influences on the family cannot be readily identified and categorised. However, their function in providing a framework for understanding the effects on the family of intervention involvement is nonetheless invaluable, as is their role in moving research in this area from a child to a family-focused approach.

Bearing in mind this constantly changing family system which exists within the wider community, the specific reasons why parental involvement in intervention can create both positive and negative effects in the family will be discussed.

### **2.3 Effects on the family of intervention involvement**

As discussed in Chapter 1, there are particular stresses associated with living with a child with autism. The move to involve parents in the role of therapist adds a new dimension. While not all parents will find it practical or desirable to become involved in interventions, for those that do, family-systems theory suggests that there will be effects on the whole family, particularly if the therapy is home-based. These will vary over the course of the intervention and be difficult to untangle, but some of the many reasons why interventions might have benefits and drawbacks for the family are outlined below.

One possible outcome is that parents' involvement as therapists will simply exacerbate existing family pressures (Cantwell & Baker, 1984; Howlin & Rutter, 1987; Ozonoff & Cathcart, 1998; Zigler, 1981). Given that part of the stress associated with living with a child with autism stems from the fact that parents feel that they lack time for themselves and the other children in the family, their involvement in an intervention could leave them with even less time and energy to meet these needs (Zigler, 1981). This may be particularly so if the intervention is very intensive or the parents have to spend time training volunteer helpers or locating sources of funding. It might also lead to parents not having the time to fulfil their own needs; and, in extreme cases, in very intensive home-based programs, parents may become marooned in isolation within their own home (Pugh, 1981). On the other hand it is possible that pressures on time can be reduced, at least in interventions which enlist the help of other non-professional therapists. While the volunteers work with the child with autism the parents have uninterrupted time for themselves, with their spouse, or the other children in the family, something which may not have been

possible prior to the intervention (Parents for the Early intervention of Autism in Children (PEACH), 1998).

Even with the assistance of helpers, parents may still put a lot of time into working with their child and may have to make a number of sacrifices to run an intervention program, such as giving up work. This could create a feeling of pressure to succeed, which is likely to be heightened if parents fundraise in the community for their intervention, or remove their child from school to work with them at home, as this will in some cases create a belief that other people expect them to produce remarkable results (Grantham & Russell, 1985). Family members may come to see themselves as excessively and personally responsible for the child's present behaviour and future development (Kozloff, 1984). This could be because many intervention programmes emphasise that the parents should feel responsible for the child's successes in skill acquisition, which inevitably leads the parents to feel that they must also take responsibility for the failures (Pugh, 1981). This is obviously less of a difficulty if the child is making progress, but when progress is less than anticipated the parents will perhaps be left with a feeling of inadequacy or feel that they have failed the child. This will be particularly so if the parents have begun the intervention with very high expectations of what can be achieved. Some parents also find that the slower rate of development in their child compared with typically developing children becomes more apparent when closely monitored in an intervention program, resulting in them feeling less satisfied about their child's progress (Selikowitz, 1997).

Some establishments which train parents in the use of interventions aim to reduce the stress connected with caring for a child with autism and being involved as their therapist by offering counselling (Hemsley *et al*, 1978; Kaufman, 1981). Parents may also come into contact with likeminded families using the same intervention, through group training, support groups and internet chat groups. Bristol (1984) notes that such informal social support networks are associated with stress reduction for parents. In addition, some of those who train parents believe that parent involvement itself reduces stress as helping their child gives parents a feeling of self-empowerment and decreases anxiety about their child's future (Cutler & Kozloff, 1987; Harris & Powers, 1984; Kozloff, 1984; Lovaas, 1993). Learning the intervention techniques can be beneficial as parents may learn new and effective ways to interact with their child, and gain great

enjoyment from the time spent together. Progress by the child, whether this be major or minor, will be a source of satisfaction for the parents.

Viewed from Minuchin's family-systems perspective, the parent and child involved in the intervention form a subsystem. The family will adapt well to intervention involvement if other family members are included in this subsystem to an extent that they are comfortable with. Difficulties will arise if the other family members feel excluded from this subsystem, or if they feel that the parent is neglecting their involvement in other subsystems because of the intervention involvement.

In terms of including other family members in the subsystem, parents are sometimes able to involve their other children directly in certain parts of the intervention programme, preventing them from feeling excluded and strengthening the relationship between the children (Luce & Dyer, 1996; PEACH, 1998). Siblings might also gain a feeling of increased responsibility and greater ability to interact successfully with their autistic brother or sister as a result of being involved in the intervention, whether this be a formal involvement or a more informal use of intervention techniques around the house. Parents may also be able to use some of the intervention techniques with their other children, in turn improving everyday parent-child interactions (Kaufman, 1994). Some aspects of interventions for children with autism reflect basic good parenting strategies, such as being focused when engaged in interaction with the child and using social praise (Kaufman 1994; Lovaas, 1987).

Family members may, however, feel excluded from the subsystem. The heightened attention on the child with autism can provoke jealousy in siblings, and there may be increased difficulties in balancing the care of the siblings with the needs of the autistic child, particularly if the siblings also expect extra 'special attention' (Angell, 1993; Hamilton, 2000; Hemsley *et al*, 1978). If the child with autism is involved in intervention for a large portion of each day, the siblings may have fewer opportunities to play with them; despite their difficulties in social interaction there is evidence that children with autism engage in a variety of play activities with their siblings (El-Ghoray & Romanczyk, 1999; Knott, Lewis, & Williams, 1995). While involving the siblings in the intervention may prevent them feeling left out, it can lead to another potential problem: if siblings become overly involved in the intervention they may take on the role of "parental



child”, and become unable to cope with the excessive responsibility and lack of fulfilment of their own needs (Minuchin, 1974). As well as problems regarding siblings, there are also potential difficulties for the marital relationship. If only one parent is involved in the intervention there is a risk that this will leave the other parent feeling excluded and unable to contribute (Pugh, 1981).

There is also the possibility that involvement in an intervention will have a detrimental effect on the relationship between the parent and the child with autism. If the parent begins to take on the role of teacher and views every interaction with the child as an opportunity for learning, the spontaneous fun side of the relationship is likely to disappear (Selikowitz, 1997).

As human ecology theory makes clear, however, the effects of - and influences on - interventions cannot be viewed as limited to the family: they must be understood as part of a bigger picture involving the community and wider society. Two specific and very concrete examples of this are the decisions made by the local educational authority regarding funding for interventions, and the willingness of community members to offer their services as helpers for those families who run intensive interventions. Although some families receive funding for home-based programs, this is still the exception rather than the rule within many local education authorities, and as a result some programs can place great financial burden on the family (Ozonoff & Cathcart, 1988; Zigler, 1981). The parents’ training in the intervention techniques may be costly, and there may also be added financial burden if parents have to give up work to run the intervention or if they have to pay additional helpers to work with their child. It is estimated that in intensive interventions, if helpers are paid, this can cost around £17,000 per year (Tissot, 1999).

There are other aspects to be considered. A number of intensive interventions rely on the use of volunteers or paid helpers to assist the parents. While this increases the number of hours of intervention that can be provided for the child, it can leave the family experiencing a loss of privacy (Birnbauer & Leach, 1993). There may also be a feeling of helplessness associated with the need to use volunteers; such intensive interventions are often used in the very early years, a time in the child’s life when any ‘teaching’ is normally done entirely by the parents (Scott, 1996). The use of volunteers will also mean that parents have to interview and hire volunteers,

provide training, terminate the employment of those who turn out to be unsuitable, and organise schedules, meetings, and ongoing feedback. For some parents this role of 'manager' will be more stressful than their work as a therapist.

For other parents, the use of volunteers may be a positive experience. Building up a team of individuals who care for the child and are enthused about being with him/her can be very rewarding. Other children in the family may enjoy meeting the helpers, and friendships can form between the family and helpers which continue after the end of the intervention (Birnbrauer & Leach, 1993).

The many effects of intervention involvement on the family, be they positive or negative, sometimes extend beyond the duration of the intervention. The interactional skills which parents learn may continue to be useful, and benefits to the child long-lasting. On the other hand Freeman (1997) notes that families may pour all their financial and emotional resources in search of the "magic bullet" when the child is young, and if the child is not cured the family may be in crisis and unable to cope when the child is older.

The numerous ways in which involvement in an intervention may affect the family, highlights the need for more in-depth research into parent involvement in intervention. The disruptions must be weighed up against the benefits with a view to evaluating the outcome for the whole family of the intervention (Golden, 1980; Howlin, 1996a). This must be considered as an ongoing process as these effects are unlikely to be static during the course of an intervention. Viewed from a family-systems perspective, the success of any intervention program will be measured not only in terms of child progress, but also in terms of its impact on other family members (Bristol, 1985). This effect on the family will be considered later in the thesis in relation to the Son-Rise Program.

## 2.4 Quantifying parent involvement in intervention

### 2.4.1 Overview

There are then both potential benefits and possible drawbacks for the family if they become involved in interventions with their child. Whether parents choose to become involved or not will depend on their individual needs, values and lifestyle, and it is crucial for professionals to respect the families' decisions (Bristol, 1985; Champion, 1985; Robbins, Dunlap, & Plenis, 1991; Wehman, 1998).

For those parents who do choose to get involved, there are a large number of interventions available for use with children with autism. One of the most obvious dimensions on which these can be distinguished is according to the degree of parental involvement:

- 'High-parent involvement' interventions – in these the parents spend a large proportion of each week working, often intensively, with the child and organising the intervention. The parent will also take primary responsibility in determining the goals and direction of the intervention from week to week, with only occasional and often indirect involvement from professional workers after any initial training,
- 'Mid-parent involvement' interventions - in these the parent is very much involved in working with the child, but with involvement of a professional therapist every week or fortnight or so. The number of hours that the parent works with the child each week is also lower than in high-parent involvement interventions,
- 'Predominately therapist-based' interventions - in these parents tend to have minimal input, with the therapy carried out by a professional therapist,
- 'Non-interactive' interventions - such as diet, medication, and vitamin supplements. Here neither parent nor therapist is interacting directly with the child to bring about change in behaviour/symptoms.

A number of interventions in each of the first three categories will be described, both to give a flavour of the variety of interventions that exist for autism, and to demonstrate the differences in the extent to which parents are involved. Note that few of these interventions are used

exclusively with children with autism; the majority are used with children with a variety of disabilities over a wide age range. However, implementation of the interventions with children on the autistic spectrum will be the focus here. Where available, details are provided on research into the effects on the family of being involved in these interventions although, in general, there have been very few studies in this area. The space devoted to each of the interventions is reflective, to some extent, of the quantity of relevant literature pertaining to its use with children with autism and to the effects on the family. Some information on evaluation studies has also been included, as effectiveness of the intervention will be a factor in determining the families' experience of it. Non-interactive interventions will not be discussed in great detail, as they do not utilise adult-child interaction as the mechanism for behavioural change, making the issues involved in their use somewhat different from the interventions in the other categories, and beyond the scope of this thesis.

#### **2.4.2 'High-parent involvement' interventions**

There are two main interventions in this category; the Son-Rise Program and the Lovaas approach (Lovaas, 1978). Patterning therapy, in which parents take the child through very early developmental skills, such as crawling, for extensive periods each day with the aim of improving their neurological organisation is another high-parent involvement intervention. However, it is no longer considered to be a reputable method for working with children (Cummins, 1988; Zigler, 1981), and has not been in widespread use for some years. It will therefore not be discussed further here. The SRP is the focus of this thesis and is described in detail in Chapter 4. It is introduced briefly here, however, with reference to the level of parent involvement, in order to enable comparison with the Lovaas method.

##### ***The Son-Rise Program***

The SRP, also known in the UK as the Option approach, was developed for children and adults with a variety of special educational needs, although it is most commonly used with children on the autistic spectrum. It is run by parents who turn one of the rooms in their home into a playroom, specifically designed to minimise distractions, in which they work with their child on a 1:1 basis - there is no interaction with other children in a typical Son-Rise session. It is a child-led approach; rather than the adult directing the child and choosing the child's activities and goals the adult joins in with the child's choice of activity, even if it is not a socially acceptable

one. A fundamental principle of the SRP is that the attitude of the adult towards the child is accepting and non-judgemental at all times.

Some families use this programme on an intensive basis, up to 80 hours a week in some cases (Kaufman, 1994). Parents sometimes use a team of volunteers to help them implement the intervention for most of the child's waking hours. In addition to their own work with their child, parents are responsible for recruiting and training volunteers, providing them with ongoing feedback, and running regular meetings to discuss the child's progress and identify future goals. Financially, the SRP is also demanding; although helpers are usually volunteers rather than paid assistants, the initial training costs around a thousand pounds, and if families are running a full-time program one parent will usually need to give up work to be at home for most of the day.

While the program therefore places potentially stressful demands on parents, it also attempts to address the stress associated with living with a child with autism. The Option Institute which provides Son-Rise training offers counselling, referred to as 'dialogues', in which parents can explore their feelings about their child and, if they so desire, work towards changing the beliefs which make them unhappy, both in relation to their child and other aspects of their life.

There have been a small number of individual case studies published on the use of the SRP (e.g. Kaufman 1981, 1994) and some families have reported that it has helped them develop a more positive attitude towards their child's autism (MacDonald & MacDonald, 1991; Kaufman, S., 1998; Roberts, 1996). However, there is a lack of wider or more substantive data, both on the effectiveness of this method, and on the effect on the family as a whole of being involved in such an intensive intervention.

### ***Lovaas method of applied behaviour analysis***

Dr. Ivar Lovaas introduced this method for use with children with autism in the 1960s. The method is based on Skinnerian operant conditioning. When the child produces appropriate behaviour this is paired with a positive reinforcer - such as food, toys or social praise - to increase the likelihood of the behaviour being repeated. According to the theory, pairing inappropriate behaviour with a negative consequence, such as the word "No!" or the withholding of positive reinforcement decreases the likelihood of such behaviour being repeated.

Children are taught appropriate social, linguistic and academic behaviour through a discrete trial approach (Keenan, Kerr, & Dillenburger, 2000). This is a sequence of teaching sessions lasting about 10 minutes, interspersed with play intervals. During each session a target behaviour is repeatedly presented (e.g. “clap your hands”), with rewards for correct responses. The child must respond correctly on a preset number of occasions before he/she is deemed to have mastered the skill. New behaviours are taught in small manageable steps, and physical or verbal prompts are decreased over time. ‘Shaping’ is also used, that is reinforcing increasingly closer approximations of target behaviour. Verbal praise is initially paired with reinforcers such as food or toys, which are faded out over time.

Although this intervention was carried out in clinics when it was initially developed, it was found that the involvement of parents as therapists within the home increased the maintenance and generalisation of intervention gains (Lovaas *et al*, 1973). This led to the development of the Lovaas approach as an intensive home-based program, run by parents with the assistance of trained helpers. In practical terms it is therefore similar to the SRP.

Evaluation of a group of 19 children with autism provided with 40 hours per week of 1:1 behavioural intervention for at least two years found that 9 of the children were judged to have “recovered” as defined by placement in a mainstream class and significant IQ gains (Lovaas, 1987). A control group of children receiving 10 hours per week of intervention did not show similar gains. Follow-up at 11.5 years showed that the cognitive and behavioural gains of the treatment group were maintained (McEachin, Smith, & Lovaas, 1993). However, the claims of this and the original work by Lovaas are still regarded by some as unsubstantiated, due to methodological flaws in the research design (Gresham & MacMillan, 1998). Other studies have though also found this approach to be effective with some children, but none have replicated the high recovery rate found in the original 1987 Lovaas study (Birnbauer & Leach, 1993; Sheinkopf & Siegel, 1998; Anderson *et al*, 1987). This may be related to differences in age of child, symptomology, and hours of intervention. In the Sheinkopf and Siegel (1998) study the differences may also be related to the fact that while the Lovaas study was a university-based research program with close supervision of parents and a high level of training for assistant therapists, their study more closely mirrored the way in which the intervention is normally

implemented, without such close support or monitoring by a university centre. Supervision and follow-up support of parents may thus be a crucial variable in the intervention outcome.

Despite the fact that this intervention demands such a high degree of parent involvement, research has focused more on evaluation studies than on effects on the family (Hastings & Johnson, 2000). One notable exception was the Birnbrauer and Leach 'Murdoch Early Intervention Project' (1993). This incorporated measures from the Parenting Stress Index (Abidin, 1986) for the 9 mothers in the treatment group whose children received an average of 20 hours per week of behavioural intervention and for mothers in the control group whose children did not receive the intervention. After two years mothers in the treatment group had a lower stress score than parents in the control group, although they were similar at the outset. The difference was not compared statistically, but does suggest that involvement in this intervention was associated with a reduction in stress. However, generalisation of these results must be tentative as families in this study were not representative of typical users of home-based behavioural interventions, as they had the services of a program co-ordinator one day per week, and they were only responsible for recruiting half of the volunteers. Also, as the study did not provide details on how many intervention hours were provided by the parents as opposed to the students each week it is difficult to assess whether this was representative of most families' experience of this intervention.

The finding that involvement in the Lovaas approach can lead to reduced stress was supported by an informal phone survey of over 200 families involved in this intervention which found that 71% of parents felt that family life was less stressful since they had begun their home-based program (Tissot, 1999). This study raises an important methodological issue – as it was not conducted by an outside party, the validity of the findings can perhaps be questioned. Howlin & Rutter (1987) note the importance of using independent researchers who have no connection with the intervention program to evaluate parental perceptions of interventions. As noted above, parents may feel pressure to be successful in their intervention. For many of the same reasons parents may be reluctant to express any criticisms they have of the intervention and its effect on their family. Using an independent researcher to conduct the research, as opposed to another parent or someone who was involved in providing the training, should make parents feel more

able to express their opinions freely. It should also be made clear to parents that critical views of the intervention they have been involved in will be welcomed (Holmes *et al*, 1982).

A more methodologically sound survey was conducted by Hastings and Johnson (2000). Their questionnaire study of 141 UK parents using this approach found that parents engaged in behaviour modification programmes for young children with autism had the same levels of stress as families of children with autism who were not involved in this intervention.

Studies examining the effect on siblings of their parent's involvement in behavioural interventions are limited but have yielded mainly positive findings. Miller and Cantwell (1976) reported a case study in which sibling involvement in a behaviour modification program increased the rate of positive interactions between siblings. It also resulted in a more consistent type of interaction within the home for the child with autism that was highly effective. Lavigne (1976) also reported positive side effects on sibling relationships in families in which siblings were involved as therapists.

While research into the SRP is conspicuous by its absence, the work relating to the Lovaas method does suggest that a high level of parental involvement is not necessarily associated with an increase in stress. It is likely that factors relating to intervention involvement aside from degree of parental input also determine stress levels (Hastings & Johnson, 2000).

#### **2.4.3 'Mid-parent involvement' interventions**

In mid-parent involvement interventions the parent again takes on the role of therapist, but works with the child for fewer hours each day than in high-parent involvement interventions such as the SRP. There is also more frequent contact with a professional therapist who helps identify goals and recommends teaching techniques. Mid-parent involvement interventions include TEACCH, Intensive Interaction, SPIN, Hanen and Portage. Holding therapy (Welch, 1983), in which parents sit the child on their lap and hold them for up to an hour each day in order to help their child overcome their avoidance of interaction, can also be considered a mid-parent involvement intervention. This particular therapy may be distressing for both parents and child as in a typical holding session the child is likely to struggle, shout and cry (Richer &



Zapella, 1989). After extensive criticism it is now rarely used so will not be discussed further here.

### **TEACCH**

TEACCH (Treatment and Education of Autistic and related Communication-handicapped Children) was established at the University of North Carolina in 1966. It is not so much an intervention as a range of services for children with autism (Schopler *et al*, 1984), but central to its ultimate aim of encouraging greater independence in the child is a structured teaching approach. This emphasises the organisation of the physical environment, and relies heavily on the use of visual cues. The teaching room is set up to keep distractions to a minimum and to make it clear to the child where to go and what to do for each activity. Timetables are provided for the child, at first in picture format, moving on to written format for more able children. These lessen the child's anxiety about transitions between tasks, and over time the child learns to cope with disruptions to the timetable. Individual tasks also emphasise a visually scheduled approach, often with pictures to prompt the child to begin each section of the activity. For example, to aid the child getting dressed, there may be pictures of each item of clothing in a row from left to right which the child must follow.

TEACCH is often used in schools, but there are also home teaching programs. A visiting therapist visits the home on a weekly basis and helps the parents decide on skills that they would like their child to achieve and models ways of working with the child to promote the acquisition of these skills. Therapist visits decrease in frequency over time to allow the parents more responsibility in implementing their child's intervention, which they use for around 30-60 minutes a day (Schopler *et al*, 1984; Ozonoff & Cathcart, 1998). Alternatively, parents can learn TEACCH structured education skills through workshops or from their child's school and then implement these skills at home. Intervention programs for each child are highly individualised but most contain the following elements: structured teaching, use of visual cues to teach more difficult skills, a schedule to help the child anticipate future events, and a communication system of some type, either gesture, pictures, signs or words (Ozonoff & Cathcart, 1998).

An evaluation of a home-based TEACCH programme involving 11 children with autism found that there were significant increases in imitation, motor and cognitive skills over a four month

period compared to a non-TEACCH control group (Ozonoff & Cathcart, 1998). In terms of effects on the parents, Schopler, Mesibov, & Baker (1982) examined parents' experience of the TEACCH program through a questionnaire study, and found that parents reported that they enjoyed their children more and felt more competent when teaching them as a result of contact with the program. Schopler *et al* noted that the use of questionnaires in their study, while providing access to a large sample, may not have provided the most accurate representation of the respondents' attitude and opinions as those who responded – 53% of those surveyed - might have had particularly strong views. This suggests that the uses of additional methods such as interview are important to corroborate findings.

Another study of 15 children involved in a four month TEACCH home Program found that, although the children with autism showed more appropriate behaviour as a result of intervention, parental stress did not reduce during the intervention period any more than it had in the waiting period before the intervention began (Short, 1984). The author suggested that this might have been because the parents were already experiencing a reduction in stress levels during the waiting period due to their expectancy of how useful the intervention would be. This is, of course, not the only possible interpretation.

### ***Intensive Interaction***

Intensive Interaction is a 1:1 method for developing early communication and sociability skills in children and adults with severe learning difficulties and those with autism (Hewett & Nind, 1989, 1998; Nind, 1997b). It was developed in the mid 1980s in response to teachers' observations that, while the problems of pupils with severe learning difficulties lay mainly in the areas of communication and sociability, these skills were difficult to teach through existing goal-orientated approaches such as behavioural techniques (Hewett, 1989). It was felt that an approach which focused on the process of reciprocal interaction rather than the achievement of specific objectives might be more suitable, so Intensive Interaction was developed.

Like the SRP this is a child-led approach in which, rather than the adult taking control of the activity, the child's lead is followed. The adult joins in the child's activity and attempts to expand on it to develop it into a communicative game, promoting skills such as eye contact, reciprocity, turn-taking, motivation and sociability (Nind & Hewett, 1994). The adult may

imitate the child's actions and vocalisations as a way of gaining the child's interest and developing interaction. There are many similarities to mother-infant interaction. For example, the adult attributes social meaning and communicative significance to seemingly non-communicative actions and vocalisations, stimuli are offered to the child but there is no insistence that the child takes these up, and the adult is responsive to the child's signals of desire to initiate, maintain or terminate an interaction (Nind, 1997a). Any behaviour on the part of the child is seen as having the potential to develop an interaction, and there is no attempt by the adult to modify atypical behaviours such as echolalia or repetitious movement. There are many similarities between this approach and the SRP in terms of techniques. The main difference is that Intensive Interaction tends not to be used for long durations each day, as is sometimes the case with the SRP.

Like TEACCH, Intensive Interaction has been largely based in schools, but recently there has been some documentation of its use by parents in the home (Taylor & Taylor, 1998). While there has not, as yet, been any research into its effectiveness when used by parents, or of the impact on the family of its use, it has been evaluated in a school context. Nind (1996) found that when it was used for a period of 12-18 months with six adults with severe learning difficulties all showed increased initiation of social contact, physical proximity and physical contact. Five of the six also showed an increase in time spent in interactive behaviours. Nind noted that there were no other significant events at the time of the onset of the intervention, thus no strong rival hypothesis for the developmental progress seen.

### ***SPIN***

SPIN is a Dutch intervention for children with a range of difficulties affecting social interaction. Parents are provided with video-feedback of play sessions with their child to help them develop successful methods of interaction, under the guidance of a home trainer (Forsyth, Kennedy, & Simpson, 1996; Houwing, 1996). The approach is not problem focused, as this may generate expectations of failure, but instead uses video clips of positive interaction to help the parents become aware of effective methods of communication and interaction (Simpson, Forsyth, & Kennedy, 1994). Time commitment varies depending on the severity of the child's symptoms, and the personal needs of the family (Trevvarthen *et al.*, 1998).

### ***Hanen***

Hanen is a speech and language therapy for children with language difficulties up to around 6 years of age. It has recently been adapted for children with autistic spectrum disorders (Sussman, 1999). The program trains parents to help their child learn to interact and communicate using opportunities that occur naturally throughout the day, such as mealtimes. It has child-led elements in its approach in common with the SRP. Strategies include following the child's lead to help develop joint attention, imitating the child to capture their attention, and modelling language for the child. Evaluations with developmentally delayed children have shown that this method increases the mother's responsiveness and labelling of words related to the child's interests, and decreases directiveness. It increases children's joint attention and vocabulary size, and leads to longer and more frequent interactive episodes (Girolametto, 1988; Tannock, Girolametto, & Siegel, 1992). Parental satisfaction with the program has been found to be high (Girolametto, Tannock, & Siegel, 1993).

### ***Portage***

This is a home-based intervention for preschool children with a range of disabilities and underlies many early intervention programmes run by local authority educational home visitors (White & Cameron, 1987). Home teachers visit the family weekly, identify new skills which parents would like their child to learn, and model behavioural methods which the parents can use to help their child acquire these skills. The parent then works with the child for 30 - 60 minutes and records the outcomes of the teaching trials. The home teacher returns each week to check the child's progress and to help identify the next skills to be taught from the 'Portage checklist' of developmental skills (Lloyd, 1986; Cameron, 1982; Glossop & Castillo, 1982).

Although little, if any, research has been carried out it seems unlikely that interventions such as SPIN, Portage, and Hanen would cause disruption to the family in terms of time involved as, apart from setting aside time for the training, the majority of the intervention work by the parent takes up less than an hour a day, and in some cases is carried out during the normal routines of the day. However, the possibility remains that involvement in such interventions can cause stress in other ways, for example in relation to the parent's feelings about the child's rate of progress.

#### **2.4.4 'Predominantly therapist-based' interventions**

In therapist-based interventions parents are not involved in providing the therapy, although they may have consultations with the professional therapist to identify appropriate goals for the child. The therapist may suggest some ideas that the parents can try at home, but within the therapy sessions all interaction will be between the professional therapist and the child.

##### ***Music therapy***

Like the SRP, music therapy focuses on developing the interpersonal relationship between the child and the adult involved in the intervention. It does so through the use of sounds and music. Music therapy does not aim to teach musical skills, but rather allows for interactive music making, generally through improvisation (Warwick, 1997). Initially the therapist uses vocalisations and musical instruments to support and foster verbalisations and actions by the child. Clinically directed musical techniques are then used to heighten the child's self-awareness and increase shared emotional communication. Clients include children and adults with a variety of difficulties, and it has been used with children with autism since the 1970s (Alvin, 1978).

Music therapy takes a variety of forms, but is usually provided by a qualified music therapist employed by health or social services, although there are music therapists in private practice. The therapist normally works on a 1:1 basis with the child, with 45 minute sessions typically provided once a week (Nordoff-Robbins Music Therapy UK, 2000). The period of therapy may be fixed or open ended, depending on the needs of the client (*ibid*). Parent involvement in a therapeutic role is unusual, but does occur in some cases (e.g. Muller & Warwick, 1993). The parents may instead be involved in observing sessions, discussing progress and identifying appropriate aims with the therapist throughout the course of intervention (Alvin & Warwick, 1991; Jordan, Jones, & Murray, 1998; Trevarthen *et al*, 1998).

Howlin (1997, 1998a) notes that, in most cases, claims of effectiveness are based largely on anecdotal reports and single case studies. More objective evaluations suggest that music therapy can increase communicative behaviours in children with autism (e.g. Edgerton, 1994), although findings of such studies are often complicated due to the considerable individual variation in progress, as well as the fact the children are often involved in other interventions concurrently (Howlin, 1997, 1998a).

### ***Occupational therapy***

Occupational therapists use a variety of intervention approaches to help the child develop skills such as self help, play, social and community skills, and visual perceptual skills (Buhagiar, 1999). Techniques include child-centred play, environmental modification, and sensory integration (Case-Smith & Miller, 1999). The latter provides graded proprioceptive, tactile and vestibular input to increase or decrease the child's arousal to sensory input as necessary (Case-Smith & Bryan, 1999).

Therapy sessions typically take place in outpatient clinics, lasting 30-60 minutes. These are primarily on a 1:1 basis, although group-based work is also used. Some occupational therapists are involved in family training and consultation with parents, but this is often secondary to 1:1 work between the therapist and child (Watling *et al*, 1999).

### ***Speech and language therapy***

Speech and language therapy for pre-verbal and verbal children addresses skills such as the production of speech, articulation, and use of gesture when communicating. For non-verbal children pre-linguistic communicative skills and alternative forms of communication such as sign language may be taught.

As with occupational therapy, sessions typically last 30-60 minutes and are either 1:1 or used with small groups. While parent involvement in the therapy sessions themselves is limited, there may be consultations with parents to help them use some of the speech therapy techniques with their child at home.

### ***Physiotherapy***

Physiotherapy focuses on gross and fine motor skills. In the case of children with autism professionally trained therapists typically work on problems of motor co-ordination, especially organising movements in relation to other people (Wing, 1996a). The therapist works with the child, normally on a 1:1 basis, but again therapeutic intervention can be carried out on a small group basis (Atherton, 1997).

### ***Facilitated communication***

This approach is based on the theory that autism is primarily an inability to make movements as intended. It is thought that some people with autism can produce more elaborate communication than they generally use when helped by a facilitator who physically supports their hand, wrist or arm while they use a communication board or computer keyboard to spell out words. Facilitators tend to be trained professionals but parents sometimes act as a facilitator for their own child (Jordan *et al*, 1998). Although the communication produced may be seen as more important than the interaction between the facilitator and the client, some authors note that the relationship built between the two during the process of the intervention is an important feature of this approach (Emerson & Grayson, 1996). For that reason this approach has been classified under 'therapist-based' rather than 'non-interactive' interventions.

There have been claims of outstanding results for facilitated communication, but the method has been greatly criticised on the grounds that, while the communication is often attributed to the client, it may in fact be the facilitator who is producing it. This question of authorship arises because the physical contact between client and facilitator leads people to question who is responsible for the 'communicative' pointing (Grayson & Emerson, 1996). It has, for example, been found that the effects are only demonstrated when the facilitator knows what the client is being asked (Prior & Cummins, 1992), and in a review of over 45 control trials involving more than 350 subjects, independent communication was confirmed in only around 6% of subjects (Howlin, 1997). The approach has been further criticised because schools have sometimes transferred resources into this approach to the detriment of the wider curriculum. Resultant typescripts have moreover, sometimes led to unrealistic expectations of what the child can achieve, resulting in inappropriate transfer to mainstream settings. In some cases there have also been unfounded accusations of sexual abuse against parents or carers made during the course of facilitation sessions (Howlin, 1997). In addition, Gould (1993) notes that the belief of some facilitated communication proponents that the true capabilities of people with autism have been neglected and denied until unlocked by this method is likely to raise painful guilt feelings in families.

As with mid-parent involvement interventions, it seems unlikely that interventions run predominantly by a therapist would cause stress in the family in relation to the amount of time

involved. Again, though there may be other sources of negative effects, such as feelings of helplessness associated with seeking the assistance of a professional therapist.

#### **2.4.5 'Non-interactive' interventions**

Non-interactive interventions include diet, medication, vitamin supplements, and auditory integration therapy. As noted earlier these do not involve interaction between the adult and child and so, with the exception of auditory integration therapy, will not be described here. Auditory integration therapy is one of the interventions used by parents in Study 1, described in the following chapter, and so will be briefly introduced here in order to familiarise the reader with the techniques involved in its use.

##### ***Auditory integration therapy***

Methods of auditory integration therapy include the 'Berard method' and the 'Tomatis method' (Howlin, 1996b). They are based on the premise that the symptoms of autism are a result of distortions in hearing which include hypersensitivity to some frequencies of sound. Treatment consists of an initial audiogram to establish the frequencies which cause the child difficulties, followed by a 10 hour listening course delivered over a period of 10 - 20 days. During the course the child listens to music which has been 'modulated' to attenuate high and low frequencies at random and filtered to dampen specific frequencies (auditory peaks) which are heard better than their adjacent frequencies (Gerlach, 1993; Rimland & Edelson, 1995; Stehli, 1995).

A trained auditory integration therapy practitioner administers the listening course. Parents are not involved in the therapeutic process, but are often asked to attend consultations with the practitioner to discuss the child's hearing sensitivities and any changes that occur in the child's behaviour over the course of treatment.

## **2.5 Overview**

There is clearly a wide range of interventions which exist for children with autism, each with varying levels of parental involvement. Although there are numerous other interventions available, this chapter has covered some of the main examples from each level, from high-parent involvement to predominately therapist-based approaches. It is important to note that these categories are not always absolute in practice. For example, some parents may use the SRP for



only a few hours a week, making it more similar to a 'mid-parent involvement' intervention than a 'high-parent involvement' intervention. Equally, a parent may be involved in a session of music therapy, or may carry out advice from a speech and language therapy session when at home, rendering these 'therapist-based interventions' more similar to 'mid-parent involvement' interventions. Such overlaps are acknowledged. The grouping here is based, however, on how these interventions are most commonly described and most frequently implemented at present.

Similarly, it is important to note that many of these interventions such as Intensive Interaction, Lovaas and the SRP are also used within schools, where they would have a much lower level of parental involvement. However, the first study in this thesis, to be described in the next chapter, explores intervention uptake outwith school, and interventions have therefore been classified according to the typical level of parent involvement when used in a non-school environment.

There are a number of dimensions along which the range of interventions described in this chapter can be categorised, such as average cost of intervention provision or typical intervention environment (home, clinic, school etc.). They can also be classified on the basis of intervention technique, for example whether they are a child-led approach or a more directive one. This is a useful distinction, and one which will be expanded on later in this thesis. However, classification according to degree of parental involvement, as outlined here, provides the most appropriate prelude to Study 1, in which recent trends in parental involvement in autism interventions are examined.

Incorporation into the intervention literature of theoretical work, such as Minuchin's family systems theory and Bronfenbrenner's human ecology theory, in recent years has led to an understanding of parent involvement in intervention as being something which affects the whole family, and must also be viewed in the context of the community and wider society. Despite this, there has been a marked lack of empirical research into the effects of intervention involvement on family functioning. Research often focuses exclusively on the efficacy of the intervention with little, if any, attention paid to the family's experience. The family perspective is often only covered in anecdotes, newspaper articles and books written by parents. These may present an unrepresentative viewpoint, however, as they tend to be written by families who have had an

extremely positive experience of the intervention (e.g. Kaufman, 1994, Maurice, 1993, Stehli, 1995).

There have, as described above, been a few exceptions to this neglect of family issues. Work by Birnbrauer and Leach (1993), Hastings and Johnson (2000), and Tissot (1999) suggests that even involvement in a very high intensity program such as Lovaas may not lead to increased stress for the family, and can even be associated with a reduction in stress. The reasons for this reduction are not fully explored, but perhaps include improvement in the child's symptomology, feelings of satisfaction from working with the child, and the time made available to spend with the rest of the family while assistant therapists work with the child.

The finding that involvement in a high-intensity intervention such as Lovaas is not associated with an increase in stress, along with the suggestion that involvement in less intensive interventions such as holding therapy may be stressful for parents, clouds the picture. It leads to the conclusion that intensity of involvement is not the only factor which determines the family's stress and overall experience of the intervention. Numerous other factors may be involved, such as parents' confidence in their ability to implement the intervention techniques, how suitable the parents think the techniques are for their child, the progress the child makes, the support and follow-up training provided for the parents, the length of time for which the family has been using the intervention, the number and age of siblings, and so on. As noted in human ecology theory, external influences will also have an effect. These may include the nature and status of parents' employment, the attitude of friends in the community to the intervention that the family are involved in, the willingness of people in the community to volunteer as helpers, and the local authority's position on funding the intervention. The few studies which have looked at the effect on the family of intervention involvement have tended to lack details on these factors, making it difficult to judge under which set of circumstances parents may have a positive experience of an intervention and which factors may lead to family difficulties. The theoretical work of Minuchin and Bronfenbrenner also suggests that longitudinal examination of the families' experience of intervention would be advantageous, as families and the communities within which they exist constantly change over time. Studies to date have rarely been longitudinal, however.

The family studies which have been conducted also raise a number of important methodological points. Firstly, the Tissot (1999) survey of stress in families using the Lovaas approach highlights the need for parents to know that research is being conducted by a researcher who is independent from those who have provided the intervention training and that they should feel able to express any concerns they have regarding its effects on the family. Schopler *et al*'s (1982) questionnaire-based research into the TEACCH approach also suggests the need for a variety of research methods in order to adequately represent the opinions of all families involved in an intervention, as use of a single methodology, such as a questionnaire, may produce a biased response.

The studies to be reported in this thesis examine the effect on the family of intervention involvement, and clearly some measure of how commonly the current generation of parents of children with autism take on the role of therapist would help to set the issues in context. Although it is obvious from the literature that there has been a general trend of increased parent involvement since the 1960s, little is known specifically about how many families choose to become involved in which kinds of intervention, and at what level of involvement. The next chapter therefore describes a questionnaire-based study of parents in one Scottish region which examines this, and looks at trends in parent involvement over recent years.

Following this, the Son-Rise Program, the focus of this thesis, will be examined in more detail. Like many of the other interventions covered in this chapter, there is a marked lack of research into the effects on family functioning when parents become involved in this type of approach. This thesis attempts to explore the experience of families using the SRP, as well as the effect of factors mentioned above, such as intensity of use, follow-up support, patterns of parental employment, confidence in using the techniques, and so on. Both large sample approaches such as questionnaire studies and more detailed case studies will be used to explore the use of this intervention by families with children with autism, including video analysis of mother-child interaction in SRP therapy sessions over a one year period of intervention.

## CHAPTER 3

### STUDY 1. SURVEY OF INTERVENTION USE IN ONE SCOTTISH REGION

#### 3.1 Introduction

As described in Chapter 2 there are numerous interventions available for use with children with autism. To date, the majority of research in this area has focused on the child, however, and relatively little has been written about the family experience, or about the uptake and patterns of use of the differing interventions. In particular, although the importance of involving parents in the treatment of their child is widely acknowledged, little is known about the decisions families make regarding the use of interventions outwith school hours, or the extent to which parents take on the role of therapist with their own child.

This chapter describes a questionnaire study which explores the uptake of ‘non-school based’ interventions. This includes interventions that parents use with their child in the home, as well as those carried out by a private or local-authority funded therapist outwith the school environment. While there has been some work into the prevalence of ‘named’ recognised interventions within schools (e.g. Jordan & Jones, 1996), less attention has been paid to those which are non-school based, despite the potential value of such work.

There are several ways in which better knowledge of the uptake of non-school based interventions could be useful. One such application is in assisting with service planning by indicating the type of information parents are likely to seek at various stages. For example, research of this kind might establish whether there is a specific time after diagnosis when parents are likely to begin using interventions and whether choice of intervention is affected by how recently the child was diagnosed, as has been suggested (Nickel, 1996).

Findings might also guide evaluation work. With so many interventions now available, research must be prioritised (Rutter, 1996), and if many parents were found to be using an unevaluated therapy, this would identify a worthwhile area for future research. Bristol *et al* (1996) have also suggested that not all people with autism are currently receiving services based on the most up-to-date knowledge available. Research into the uptake of interventions could help to establish whether this is indeed common. For example, if many parents were still using an intervention which previous research has shown to be ineffective, such as patterning, this would suggest that information is not filtering down from academic research to parents, and steps would need to be taken to remedy this.

As noted in Chapter 2, establishing how many parents take on the role of therapist and which interventions they use is also of value in and of itself as it is a necessary first step in examining the effects on the family of intervention involvement. This thesis specifically explores family involvement in the Son-Rise Program, and a first logical step is to set this particular intervention in context by looking at the proportion of families that use this approach, how common it is compared to other interventions, and which type of children it tends to be used with in terms of age and diagnosis. These issues are all covered in the study to be reported below.

### **3.1.1 Previous research into intervention uptake**

Although there are a number of ways in which determining the uptake of non-school based interventions could inform future research and parent-support provision, there have been few previous studies in this area. The little research carried out has been largely based in the United States and has found a large uptake of non-school based interventions. Nickel and Stratton (1995) investigated use of 'nonstandard' interventions (such as vitamin supplements), the majority of which were presumably non-school based. They surveyed 455 parents of children with autism and found that 50% had tried at least one 'nonstandard' intervention. Another survey examined use of pharmacological interventions, again likely to be non-school based. In the sample of 838 children with autism 53% were taking some form of medication or vitamin treatment (Aman *et al*, 1995). Given that each of these studies investigated use of only some of the non-school based interventions available it is likely that the total percentage of U.S. families using non-school based interventions is higher than 50%.

There are likely to be differences between countries in non-school based intervention uptake, for a number of reasons including availability of information on various approaches and attitudes towards different types of intervention such as medication. Results from U.S. studies cannot therefore safely be generalised to this country and research is required to establish U.K. trends in uptake of non-school based interventions.

One UK-based study was the Jordan and Jones (1996) report on educational provision for children with autism in Scotland, in which 38% of the parents surveyed said that either the school or they themselves used a particular intervention with their child. Music therapy, special diet and music-assisted communication were particularly common. However, this did not distinguish between those interventions used in school, and those which were non-school based, making it likely that the percentage of Scottish parents using interventions outwith school was lower than 38%. This is also suggested by the results of a survey carried out by Howlin and Moore (1997). They found that around a fifth of families indicated that they had not been offered help of any kind following diagnosis, around 10% were offered language

therapy, and only around 3% were offered interventions at home such as Portage and behavioural programs. While parents may, of course, have later sought out other interventions in addition to the ones offered at diagnosis, the small proportion offered interventions at this time does indicate that there may be a much lower level of intervention use in the UK than in the States.

It is clear that the literature in this area is sparse. Findings from the States cannot be generalised and UK research has not, to date, explored the uptake of non-school based intervention as distinct from school-based interventions. Research is required to establish not only how many children are currently involved in non-school based interventions, but also which particular interventions are being used.

A number of additional questions can be explored through research into intervention uptake. These are discussed below, and include consideration of how many different interventions families use at the same time; the extent to which parents take on the role of therapist; and how interventions are funded.

### **3.1.2 Use of concurrent interventions**

It is important to establish whether parents use one intervention alone or use a combination of approaches with their child. Jordan *et al* (1998) note that one of the difficulties when trying to evaluate the effectiveness of any autism intervention by measuring change in children during the programme is that parents may try more than one approach simultaneously. Anecdotal reports suggest that in the United States it is more common for children to be receiving multiple interventions than any one single intervention. Despite this, research into interventions often omits detail on the quality and quantity of learning experiences outside the defined “treatment package”, and disregards their role in accounting for developmental change (Prizant & Rubin, 1999). There is currently no research to suggest whether use of multiple interventions is the norm in the UK and if so, what the effects of this might be.

### **3.1.3 Quantifying parental involvement in interventions**

As well as differences between families in the number of interventions used, there may also be differences in the level of parental involvement. While some parents wish to take on the role of therapist, some families find this neither practical nor desirable. Family systems theory, outlined in Chapter 2, suggests that when parents do become involved in interventions this will affect the whole family. Prior to research work in this area, it would be helpful to ascertain the proportion of families in which parents take on the role of therapist to determine the extent to which family involvement is a research priority.

As described in Chapter 2, the level of parent involvement has changed over time. In the 1960s parents were not routinely involved in the treatment of their children but by the early 1970s research showing the effectiveness of involving families in the treatment of their child led to a change in the role of parents. Now, the importance of involving parents in the intervention of their child, whether this be in an advisory or therapist role, is widely acknowledged (Shields, 1999; Trevarthen *et al*, 1998). Although the overall change in parental involvement since the 1960s has been documented, little is known specifically about the trends over the past two decades. However, it would seem reasonable to predict that parent involvement in intervention is likely to continue to grow, given the increased availability of information on parent-run interventions via the television and internet, and the development of an ethos of ‘parent partnership’ within the educational and health systems (DfEE, 1997).

In Chapter 2 a categorisation system for autism interventions relating to the degree of parental involvement was described. Interventions were categorised according to how they are most commonly described and implemented at present in a non-school based environment (table 3.1).

Table 3.1: Level of typical parent involvement in interventions for autism

High parent involvement	Mid parent involvement	Therapist-based	Non-interactive
Son-Rise Program Lovaas Patterning	TEACCH Intensive Interaction SPIN Portage Hanen Holding therapy	Speech therapy Occupational therapy Physiotherapy Music therapy Facilitated communication	Diet Medication Vitamins Auditory integration

Using these categories the level of current parent involvement in interventions and changes over time can be explored. Although parental involvement may have increased over recent years it would seem unlikely that ‘high-parent involvement’ interventions will be the dominant form of intervention. Such interventions tend to be relatively expensive and also require that at least one parent is not in full-time employment, something which is not possible for many families. Jordan (1996) also notes that it is rare to find children taken out of education to use full-time therapies such as these.

3.1.4 Intervention funding

For many families the extent of their involvement in a therapist role may be interlinked with how the intervention is funded. While self-funding interventions may be an option for some families, a greater number are likely to use interventions provided by the local authority, such as speech and language therapy.

Interventions can be split into two groups according to who funds them (table 3.2). The first group are therapies which tend to be funded by local authority health and education services. The second group are the ‘privately funded interventions’, those which are not provided by health and education services. For these interventions parents usually need either to seek out and pay for a private therapist or to implement the intervention themselves.

Table 3.2: Local authority funded and privately funded interventions

Local authority funded interventions	Privately funded interventions
Speech therapy	Son-Rise Program
Occupational therapy	Lovaas
Physiotherapy	Patterning
Medication	TEACCH
Portage	Holding therapy
Hanen	Intensive Interaction
SPIN	Diet
	Auditory integration therapy
	Music therapy
	Vitamin supplements

These categories are not always absolute. For example, some families may use a private speech and language therapist, and music therapy may sometimes be provided by education services. The division here is based on how these interventions are most commonly described and funded at present. There have been an increasing number of cases in which LEAs have funded families using the Lovaas method (PEACH, 1998) but this has not been classified here as ‘local authority funded’ as by no means all LEAs currently provide funding for this intervention (Hastings & Johnson, 2000).

Uptake of local authority funded interventions may be more common than privately funded interventions because they are more accessible in terms of cost. Information on local authority funded interventions may be more readily available as parents may be offered these interventions following the diagnostic process whereas it may be more difficult to access information and training on privately funded interventions. Local authority funded interventions also carry with them assurances regarding the level of therapist training, another consideration for parents when choosing interventions.



In terms of changes in uptake over time, Rogers (1999) notes that increased identification of autism and earlier diagnosis means that more families are seeking assistance from educational and health services. Unless this rise in identification has been matched by an increased level of funding for these services it would seem likely that the proportion of children who receive local authority funded interventions such as speech and language therapy will have decreased over time or that the number of sessions offered would have been reduced.

### **3.1.5 Characteristics of children involved in non-school based interventions**

From the information that is available to date, it is likely that many children will not be involved in any form of non-school based intervention. For some parents this may reflect parental satisfaction with their child's development through the educational system. For some families though it may be due to difficulty in locating an intervention which they feel is suitable for their particular child or due to a problem in accessing information on interventions in general.

Identifying the typical age and diagnosis of those children who are involved in non-school based interventions compared to those who are not may help to establish whether there are, in fact, differences between the group of families who use such interventions and those who do not. If group differences are found to exist, the reasons for this should be considered.

### **3.1.6 Use of named interventions in the school environment**

Although the focus of this study is on non-school based interventions, it is useful to compare the uptake of these with the uptake of school-based interventions, in order to establish whether similar interventions are used in both environments. Ozonoff and Cathcart (1998) note that, since consistency is a primary principle of working with children with autism, it is possible that using different interventions at school and home may cause confusion for the child.

### **3.1.7 Prevalence and pattern of use of the Son-Rise Program**

Some authors suggest that intensive interventions are becoming more common due to parents' higher expectations of outcomes in autism, due to the influence of the early intervention literature (Rogers, 1999). Uptake of the SRP in particular may have increased over recent years due to greater media attention and the establishment of training courses in this country: previously families had to travel to the States for training. It would therefore be advantageous to find out which type of children this intervention is used with and the usual duration of use, as this would allow research to be planned which involved children and families who represented typical users of the SRP.

### 3.2 Research questions

This questionnaire study aimed to address each of the questions raised above and to examine in particular how the SRP fits into current patterns of intervention uptake. The study aimed to involve all parents in one Scottish region with children on the autistic spectrum, and attempted to answer the following questions:

- (1) What is the current prevalence and pattern of use of non-school based interventions?
  - How many children are involved in non-school based interventions?
  - How common are the various types of intervention?
  - Do families use only one intervention or follow a more eclectic approach?
  - How many of the interventions in current use are those which are typically described in the literature (see table 3.1 – p50) as being ‘high-parent involvement’, ‘mid-parent involvement’, or ‘predominantly therapist-based’, and how many ‘non-interactive’?
  - How many of the interventions in current use are those which are typically described in the literature (see table 3.2 – p51) as typically being funded by the local authority and how many as privately funded?
  - At what point after diagnosis do children become involved in interventions?
- (2) Are there differences between previous and current prevalence and patterns of use?
  - Were any interventions used in the past which are not in current use?
  - Are any interventions in current use which were not used in the past?
  - Has the proportion of families using non-school based interventions changed over time?
  - Have there been changes over time in the type of interventions used?
- (3) Which non-school based interventions do families plan to become involved in in the future?
- (4) Are there differences between children who are involved in non-school based interventions and those that are not?
  - In terms of age?
  - In terms of diagnosis?
- (5) What is the prevalence and pattern of use of named interventions at preschool/school?
- (6) What is the prevalence and pattern of use of the SRP?

### **3.3 Methodology**

#### **3.3.1 Design**

The questionnaire aimed to gather information on children in Lothian region aged 18 and under who had been diagnosed with an autistic spectrum disorder. Information on current non-school based intervention use was requested, as well as information on previous and planned future use. As the period of previous intervention use would span more than a decade for some children, parents were given a list of interventions to aid recall. Parents were also asked about their child's involvement in named interventions at preschool/school, as well as their views on the particular interventions which they had used. Basic demographic information such as age and diagnosis was also requested. A copy of the full questionnaire can be found in Appendix B. In the questionnaire it was made clear to parents that they were under no obligation to participate in the study if they did not wish to, and that their personal details would remain confidential (see Appendix A for details of ethical considerations).

Parents were not specifically asked about their level of involvement in each of the interventions they had used, nor for details of how each of these had been funded. Maximizing the return rate was a central consideration and it was felt that including questions on these areas would deter parents from returning the questionnaire, as it would require disclosure of personal financial matters and also greatly lengthen the amount of time taken to complete it. Instead, analysis was based on the level of parental involvement and source of funding commonly stated in the literature in relation to each intervention (tables 3.1 & 3.2 – see pp 50 & 51).

The questionnaire was piloted on one family with several years of involvement in various interventions, in order to verify the clarity and sensitivity of the questions. The family commented that none of the questions seemed unclear or insensitive, and that the questionnaire was not over-lengthy.

#### **3.3.2 Participants**

Questionnaires were initially sent out through the Lothian Autistic Society (LAS), a support organisation for families and carers of people with autism in the Lothian region. One questionnaire was sent out to the family of each child under 18, to be completed by the parent or guardian. 92 questionnaires were distributed to 87 Lothian families: five of the families had two children on the autistic spectrum and so were asked to fill in an additional questionnaire for the second child. Follow-up reminder letters were sent to families who did not initially reply, as this has been shown to increase response rate (Heberlein & Baumgartner, 1978). Of the 92 questionnaires 63 were returned, giving a return rate of 68%.

As findings might be unrepresentative if responses were only to come from parents who chose to join a support group (Aman *et al*, 1995) further questionnaires were sent out to parents/guardians of children with autistic spectrum disorders who were registered on the database of the local children's hospital, but were not members of the LAS. This database contained an additional 64 children (54 diagnosed with autism, 10 with Asperger syndrome). On the advice of the consultant paediatrician in charge of the database, the parents of 1 of the children with Asperger syndrome and 24 of the children with autism were not approached as it was thought that these families were currently in very stressful situations and would find it too upsetting to be contacted about the research. Consequently 25 of the families in total were not approached. The remaining 39 families were sent questionnaires. 21 replied, giving a response rate of 54%.

In total 156 children on the autistic spectrum were identified in the Lothian region. Families of 131 of these were sent questionnaires and 84 replied, an overall response rate of 64%. Although this rate was relatively high for a questionnaire-based study, it is nevertheless possible that parents who are involved in approaches with their child may have been more motivated to return the questionnaire. This needs to be borne in mind when interpreting the results.

### 3.4 Questionnaire findings

#### 3.4.1 Child characteristics

##### *Child's age*

Child's age at the end of December 1998, i.e. the end of the data collection period, was used in data analysis. Minimum age in the sample was 2 years, and maximum 16 years; average age was 7 years 8 months. As table 3.3 shows the highest percentage of children were between 5 and 7 years old, with two-thirds falling in the 5-11 age range.

Table 3.3: Age of children of respondents

Age group	No. of children (%)
2;00 - 4;11 years	13 (15%)
5;00 - 7;11 years	31 (37%)
8;00 - 10;11 years	25 (30%)
11+ years	15 (18%)

In order to ascertain whether the age of the children whose parents returned the questionnaire was representative of the total population of all children with autistic spectrum disorders in Lothian, the average age of the sample children (7 years 8 months) was compared with:

- (5) the average age of all those children whose parents had been sent a questionnaire, but had not returned it.
- (6) the average age of the children with autistic spectrum disorders in Lothian whose parents had not been sent a questionnaire.

The average age in these 2 groups was 9 years 3 months and 10 years 2 months respectively, significantly higher in both cases than the mean age of respondent children ( $U = 1513$ ,  $p < 0.05$  and  $U = 663$ ,  $p < 0.05$  respectively)<sup>1</sup>. The average age of the whole population of children with autistic spectrum disorders in Lothian was 8 years 7 months.

The sample of Lothian children with autistic spectrum disorders whose parents did return the questionnaire were then younger than those who did not. This may be because younger children are perhaps more likely to be involved in interventions, making their parents more likely to return the questionnaire. Alternatively, parents of older children may have more 'questionnaire fatigue' than parents of younger children, given the abundance of autism research in recent years.

### **3.4.2 Child's diagnosis**

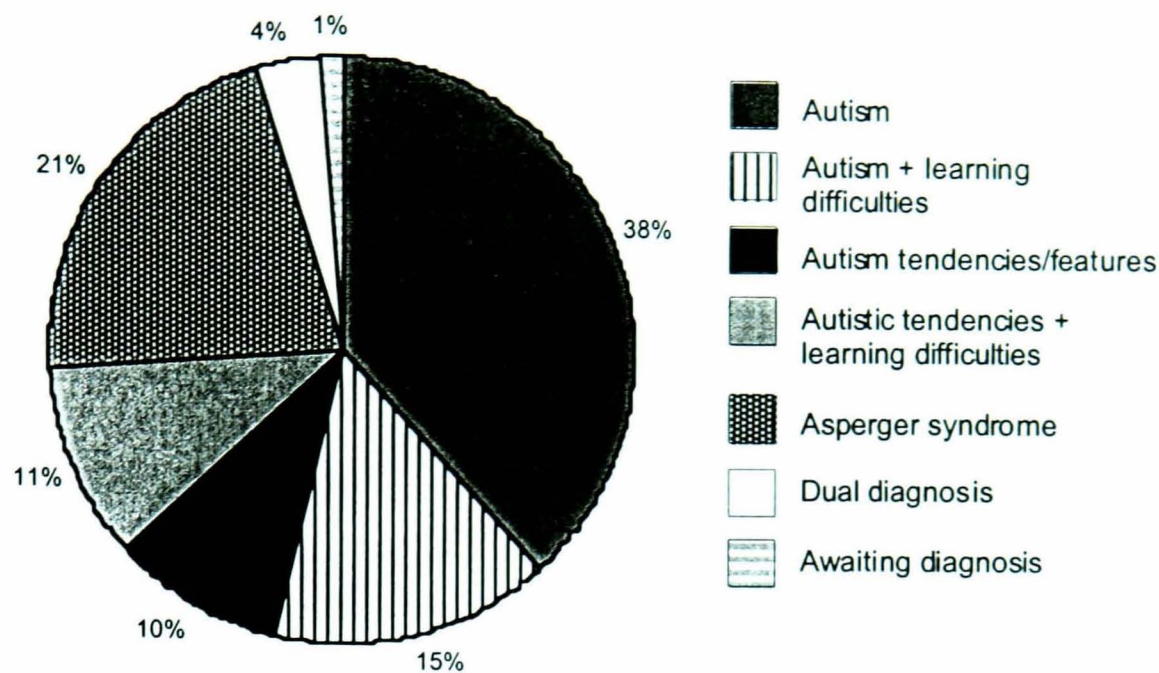
As figure 3.1 shows, the most common diagnosis was autism (53%), followed by autistic tendencies (21%) and Asperger syndrome (21%). There were perhaps fewer children than expected with learning difficulties, only 29% altogether (15% autism plus learning difficulties, 11% autistic tendencies plus learning difficulties, 3% dual diagnosis plus learning difficulties). This may be because a large proportion of the children were still fairly young and may not have been fully assessed. In four cases of autism parents specifically mentioned that it had not yet been established whether their child had learning difficulties or not (these children were therefore included in the category of 'autism' in figure 3.1).

Three children (4%) had received a dual diagnosis. In these cases the child had been seen by two professionals each of whom had given a different diagnosis. In two cases this was of 'autism and autistic tendencies' and in one case it was 'Asperger syndrome and autistic tendencies'. In two of these three cases there were also confirmed additional learning

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<sup>1</sup> An alpha value of 0.05 has been used throughout this thesis. Values greater than 0.05 will be reported as non-significant (ns).

difficulties. Lack of an unequivocal diagnosis can be dissatisfying for parents and may make it difficult to plan appropriate education and intervention (Howlin and Moore, 1997).



Notes:

- (1) Autism: This category included children with a diagnosis of autism, high-functioning autism, and autism with additional difficulties (but excluding diagnosed learning difficulties). Additional difficulties included epilepsy, De Soto's syndrome, deafness, problem of motor coordination, and severe communication disorder. This group also encompassed those children with autism where the parents were unsure if there were additional learning difficulties or not.
- (2) Autistic tendencies/features: This category also included children diagnosed with autistic spectrum disorder (n = 3).

Figure 3.1: Child's diagnosis

### 3.4.3 Age of diagnosis

The lowest age at diagnosis was 1 year 6 months, highest was 11 years, and average was 4 years 2 months. If parents indicated several ages of diagnosis (e.g. if diagnosis had changed from autism to Asperger syndrome) the age of the first diagnosis of an autistic spectrum disorder was taken as this would have been the time from which parents might first have considered using an intervention with their child.

**3.4.2 Non-school based interventions - exclusions**

Augmented communication approaches such as sign language and communication through symbols/pictures were not included in the analysis of current or previously used interventions, because although such methods have aims in common with interventions (improving communication and hence improving social interaction and behaviour), they represent systems of communication for the child to learn, rather than interventions with a predominantly ‘therapeutic focus’. 15 families were currently using augmented communication, 2 families had previously used it but were doing so no longer, and 2 families were considering using it in the future.

**3.4.3 Current interventions**

*Number of families currently involved in non-school based interventions*

Families split almost evenly between those who were involved in interventions outwith preschool/school and those who were not. Of the 84 children in the sample, 43 (51%) were not currently involved in interventions outwith school, while the other 41 (49%) children were involved in at least one (table 3.4).

*Concurrent intervention use*

Of the 41 children currently involved in interventions, the majority (30 children) were involved in only one approach; only 11 were involved in more than one kind of non-school based intervention (table 3.4). This suggests that the families that are involved in such interventions tend not to follow an eclectic approach outwith school (although the child may of course be involved in other approaches at school).

Table 3.4: Number of non-school based interventions children were currently involved in

No. of interventions	No. of children (%)
0	43 (51%)
1	30 (36%)
2	8 (9 %)
3	3 (4%)

### *Types of intervention in current use*

As table 3.5 shows, speech and language therapy was by far the most commonly used intervention. Music therapy, diet and the SRP were next in popularity, albeit far behind. With the exception of Supernuthera vitamin supplements, used by 2 families, there were no pharmaceutical treatments used.

Table 3.5: Types of non-school based interventions currently in use

Type of intervention	No. children
Speech and language therapy (excluding Hanen)	24
Music therapy	7
Diet *	6
Son-Rise Program	4
Behaviour modification (Lovaas)	2
Auditory intervention (e.g. Tomatis)	2
Supernuthera vitamin supplement	2
TEACCH	2
Hanen	2
Occupational therapy	1
Physiotherapy	1
Intensive Interaction	1
Portage	1

\* In 2 cases this was a gluten-free diet, in 4 cases type of diet was not specified.

### *Level of parental involvement in current interventions*

If all the interventions in current use (table 3.5) are added together it can be seen that 55 interventions were in current use. Interventions in current use were grouped according to the degree of typical parental involvement in each, as outlined in the introduction (table 3.1 – p50). Table 3.6 shows that currently the most common form of intervention was therapist-based, with 33 of the 55 current interventions being of this type; in the majority of cases this was speech and language therapy. 'Mid' and 'high' parent involvement interventions were the least common, but together made up 12 (22%) of the 55 interventions in current use. In cases where families were using multiple interventions in all but one case this included at least one therapist-based intervention.

Table 3.6: Level of parental involvement in current interventions

Type of intervention	No. of these interventions used
High-parent involvement interventions	6
Mid-parent involvement interventions	6
Therapist-based interventions	33
Non-interactive interventions	10



Currently parents of 11 children had taken on the role of their child’s therapist to some degree; 5 involved in high-parent involvement interventions, 5 involved in mid-parent involvement intervention, and 1 family using both. A therapist role was therefore taken on by 27% of the families using interventions (13% of the whole sample).

***Funding for interventions***

Interventions in current use were also grouped according to the typical source of funding, as outlined in the introduction (table 3.2 – p51). Table 3.7 shows that about half were those typically funded by the local authority and about half were those typically privately funded. In cases where families were using multiple interventions in all but two cases this included one which was funded by the local authority.

Table 3.7: Funding of current interventions

Type of intervention	No. of these interventions used
Local authority funded interventions	29
Privately funded interventions	26

**3.4.4 Previous interventions**

Parents were also asked about any interventions that they had previously used with their child, but were no longer using. They were asked when and for how long these interventions were used.

***How many families have been involved in non-school based interventions at some point?***

Examination of previous intervention usage, when combined with current intervention usage showed that 55 (65%) of the children in the sample have been involved in non-school based interventions at some point in their lives. Only 29 (35%) had never been involved in anything other than school-based interventions.

***Which interventions were used previously?***

As table 3.8 shows, the types of interventions previously used by families did not differ greatly from those currently used, with speech and language therapy and music therapy being the most common, followed by diet.

Table 3.8: Non-school based interventions used previously

Type of intervention	No. children
Speech and language therapy (excluding Hanen)	15
Music therapy	6
Diet *	4
Occupational therapy	4
Son-Rise Program	3
Auditory intervention (e.g. Tomatis)	3
Supernuthera vitamin supplement	2
Holding therapy	2
Hanen	1
TEACCH	1
Facilitated communication	1
Cognitive relaxation	1
Cognitive therapy	1
Behaviour modification (Lovaas)	1
Patterning-type interventions	1
SPIN	1
Portage	1

\* In 1 case this was a gluten-free diet, in 3 cases type of diet was not specified.

### 3.4.5 Differences between previous and current interventions

Some interventions were identified that had been previously used by some parents but were not in the current usage table, such as facilitated communication, holding therapy, and SPIN. Facilitated communication had not been used by any family in the sample for the past 12 years, holding therapy for the past 4 years, and SPIN for the past 2 years.

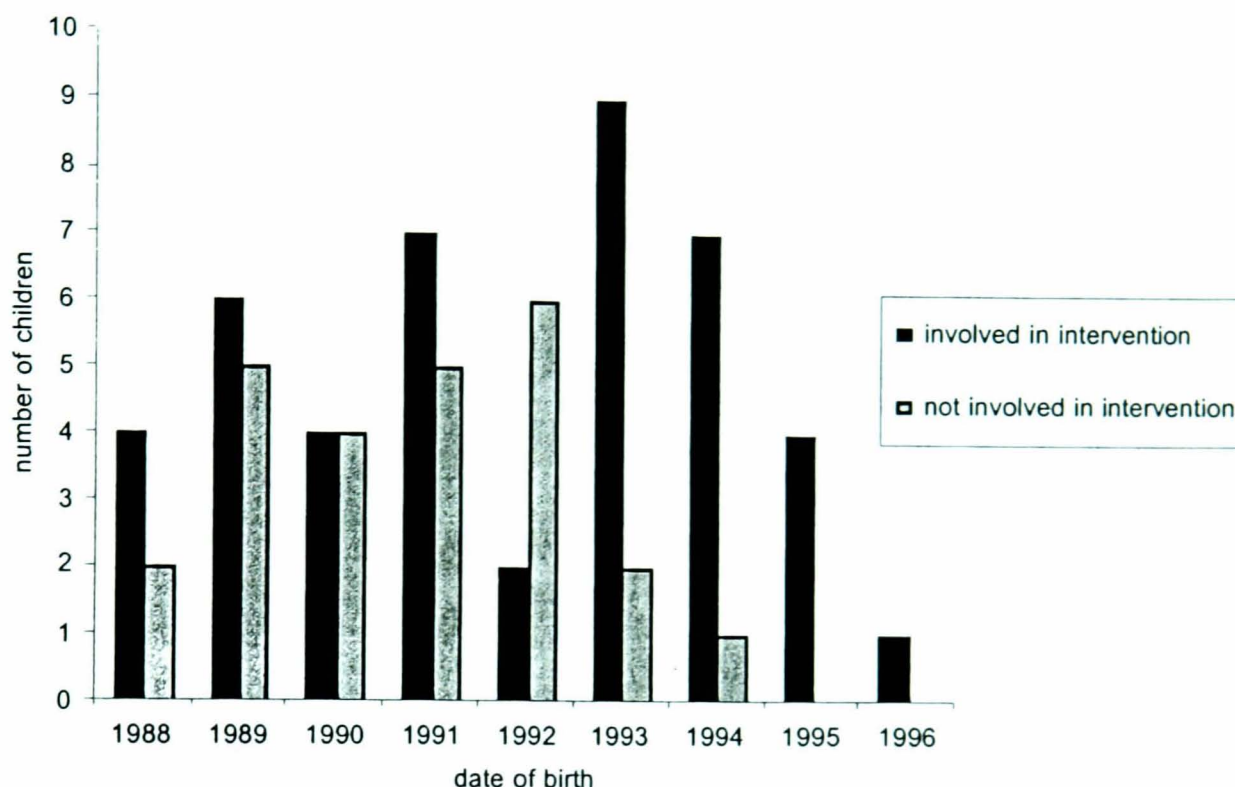
Intensive Interaction, begun by one family in 1997, was the only intervention which was in current usage, but had not previously been used by any families in the sample. Intensive Interaction, Hanen and the SRP had all increased in usage over time. This may suggest a move towards child-led interventions in recent years, although the numbers involved are too small to confirm or deny this.

### 3.4.6 Time of intervention implementation – relation to time of diagnosis

Of the parents of the 55 children who had been involved in interventions, information on date of diagnosis and date of first intervention use was available for 47. Of these 19 had begun before their child had been diagnosed with an autistic spectrum disorder. The maximum number of years before diagnosis that an intervention had been implemented was 6 years, and the average was 1 year 10 months. For families who had begun intervention before diagnosis, this was almost always speech and language therapy. 28 families began intervention after diagnosis. The maximum number of years between diagnosis and intervention implementation was 4 years; typically intervention use followed diagnosis by less than a year, on average 10 months after the child was identified as having an autistic spectrum disorder.

### 3.4.7 Changes in intervention uptake over time

To examine whether the uptake of non-school based interventions has changed over time, the children's birth dates were plotted against their history of intervention use. Figure 3.2 shows how many children from the sample were born in each year and whether these children had been involved in a non-school based intervention at any point. With the exception of children born in one particular year (1992), involvement in intervention was as, or more common than, non-involvement.



Note: the number of children born each year prior to 1988 was too small to be meaningfully included.

Figure 3.2: Year of birth in relation to involvement in non-school based interventions

The number of children born in any given year was small, making it difficult to draw definite conclusions. Figure 3.2 does though suggest that the children born more recently (since 1993) were more likely to have become involved in non-school based interventions than children born prior to 1993. Of the 84 children in the sample, 60 were born prior to 1993 and 24 were born after 1993 and table 3.9 shows how many children were involved in non-school based interventions. Children born after 1993 were significantly more likely to have been involved in a non-school based intervention than those born prior to 1993 ( $\chi^2=6.77$ ,  $p<0.01$ ,  $df=1$ ). This, however, may have been an artefact of the composition of the sample; not all children born since 1993 would have been diagnosed at the time of this study, and it could be that those identified at younger ages have more marked difficulties, making parents more inclined to use interventions.

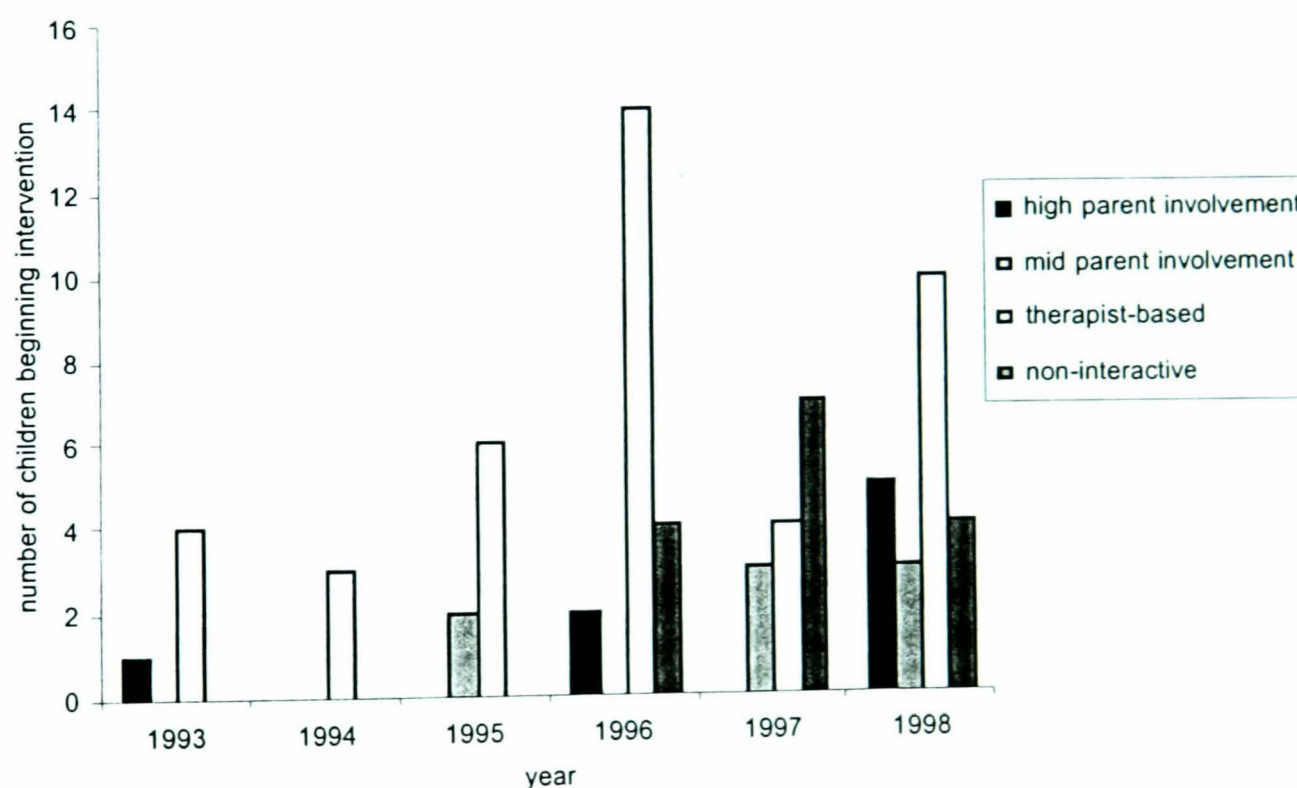
Table 3.9: Number of children involved in non-school based interventions pre and post 1993

Year of birth	No. involved in interventions	No. not involved in interventions
1982 - 1993	34	26
1993 - 1996	21	3*

\*p&lt;0.01

### 3.4.8 Changes in level of parental involvement over time

Uptake of the four intervention types was examined to establish whether there have been changes in use over recent years (figure 3.3). Again, the numbers involved in each intervention type were small, making it difficult to draw definite conclusions. However, it does appear that while therapist-based interventions have remained the most popular over the years, uptake of the other types of intervention has begun to increase. For example, non-interactive interventions were not in use at all prior to 1996, but have been used by some parents in every year since then. Uptake of high parent involvement interventions also seems to have increased, particularly in 1998. The results seem to suggest that parent involvement in intervention has increased somewhat over time.



Notes: (i) prior to 1993 the number of children involved in interventions was too small to be meaningfully included.  
(ii) cases in which dates of intervention usage were not given have had to be excluded

Figure 3.3: Difference in uptake of the four intervention types: 1993-1998

3.4.9 Changes in sources of funding over time

The uptake of local authority funded versus privately funded interventions can also be examined for changes over recent years. Table 3.10 shows how many interventions were begun each year, and how these were funded. Note that figures for 1988-1995 were collapsed, as the number of interventions begun in any one year over this period was very small. Although the small figures in all years make it difficult to draw definite conclusions, they do seem to indicate that uptake of privately funded interventions has increased over recent years whereas uptake of local authority funded interventions has decreased. While it is often unwise to convert such small figures into percentages, in this instance it does make the trend more apparent (figure 3.4).

Table 3.10: Uptake of local authority funded and privately funded interventions 1988-1998

Year	Total no. of interventions begun*	no. of local authority funded interventions begun	no. of privately funded interventions begun
1988-1995	27	21	6
1996	20	14	6
1997	14	5	9
1998	22	6	16

\* cases in which dates of intervention usage were not given have had to be excluded (n=20)

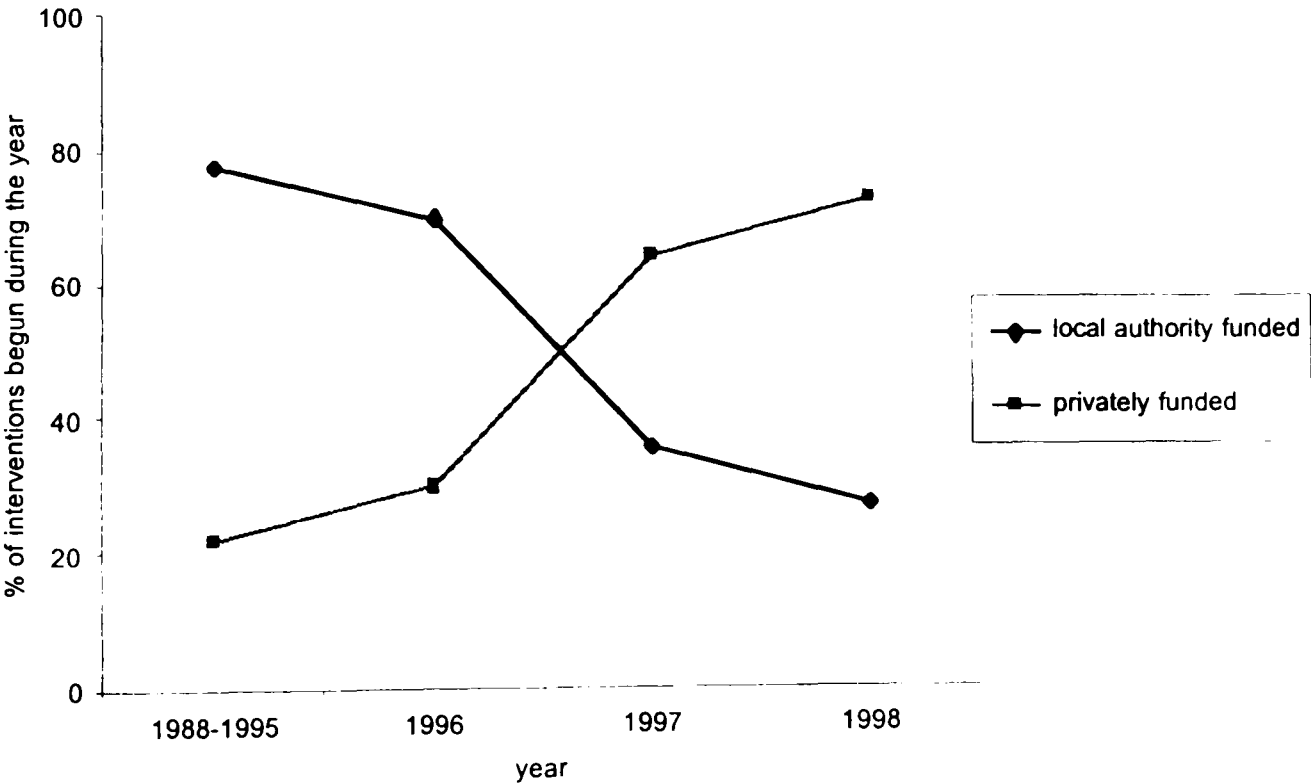


Fig 3.4: Uptake of local authority funded and privately funded interventions 1988-1998



**3.4.10 Links between child characteristics and non-school based intervention uptake**

*Differences in age between those currently involved in interventions and those not involved*

The average age of children currently involved in interventions was 6 years 8 months. Children not currently involved in interventions had an average age of 8 years 9 months and were significantly older (U = 557.5, p < 0.05).

*Differences in age between those currently involved in local authority and privately funded interventions and those not involved*

Table 3.11 shows that children began interventions typically funded by the local education authority at a significantly earlier age than those beginning typically privately funded interventions (U = 620, p<0.05).

Table 3.11: Average age of children when beginning the 2 intervention funding types

Type of Intervention	Average age of children at start	No.
Local authority funded	3 yrs 10 months	44
Privately funded	5 yrs 3 months*	39

\* p < 0.05

*Relation between diagnosis and intervention uptake*

As table 3.12 shows, no single diagnostic group stood out from the others in terms of level of intervention use, with around a third to two thirds of each group currently using interventions. ‘Autism + other difficulties’ is the only group where none of the children was currently involved in intervention, although numbers were also low in several other categories. With numbers in the groups being so small it is not possible to establish whether these differences are significant or not.

Table 3.12: Relation between diagnostic category and non-school based intervention use

Diagnosis	No.	No. currently using	No. ever used
autism	26	14	16
autism + learning difficulties	13	7	11
autism + other difficulties	6	0	1
autistic tendencies/features	5	3	4
autistic tendencies + learning difficulties	9	6	6
autistic tendencies + other difficulties	3	1	1
Asperger syndrome	18	7	12
combination	3	2	3
awaiting diagnosis	1	1	1

3.4.11 Future Interventions

*How many families planned to become further involved in non-school based interventions over the next 3 years?*

As table 3.13 shows, the families of the majority of children (79%) had no plans to become involved in additional interventions within the next 3 years.

Table 3.13: Number of additional interventions planned for use within next 3 years

No. of planned additional interventions	No. of children (%)
0	66 (79%)
1	12 (14%)
2	6 ( 7%)

*Which type of future interventions were planned?*

As table 3.14 shows the most common interventions that parents planned to use with their children in the future were the SRP and the music therapy.

Table 3.14: Types of planned future interventions

Type of intervention	No. children
Son-Rise Program	6
Music therapy	6
TEACCH	3
Diet	2
Auditory intervention (incl. Tomatis)	2
Social skills course	1
Behaviour modification (Lovaas)	1
Hanen	1
Occupational therapy	1
Physiotherapy	1

3.4.12 Interventions within preschool/school

*How many children were involved in interventions at preschool/school?*

Of the 83 children currently attending preschool or school, the parents of 36 (43%) reported that their child was involved in a named intervention at school. The other 47 children (57%) were either not involved in intervention at school or parents were unaware of any such intervention (i.e. this section of questionnaire was left blank).

***How many different types of interventions were used at preschool/school?***

Table 3.15 shows how many different interventions were in use in preschool/school settings. This shows that an eclectic approach is more likely within school than outwith; as we have seen (table 3.4 – p58) only 13% of children were currently involved in more than one non-school based intervention, whereas at school 26% were involved in more than one approach.

Table 3.15: Number of interventions children were currently involved in at preschool/school

No. of interventions	No. of children (%)
0 (or not specified)	47 (57%)
1	14 (17%)
2	17 (20%)
3	2 (2%)
4	3 (4%)

***Which interventions were most commonly used at preschool/school?***

Table 3.16 shows the interventions that children were involved in at school. In many cases it was reported that the school used elements of the intervention rather than the whole approach. TEACCH and Intensive Interaction were more frequently used at school than outwith, but speech and language therapy and music therapy remained among the most commonly used approaches (as was the case with interventions used outwith school). The parents of 18 of the children also reported that their child used augmented communication at school.

Table 3.16: Types of intervention that children were currently involved in at preschool/school

Type of intervention	No. of children
Speech and language therapy	26
TEACCH	16
Music therapy	7
Son-Rise Program	4
Intensive Interaction	5
Aromatherapy	1
Dance therapy	1
Gentle teaching	1
Higashi	1
Low intrusion teaching	1
Portage	1
Physiotherapy	1
Occupational therapy	1



**3.4.13 Interventions used across settings**

In total 64 (76%) of the children in the sample were currently involved in named interventions either at preschool/school or outwith, with only 20 children (24%) not reported as being involved in any named intervention in either setting. 74 (88%) of the children had been involved in a named intervention either at preschool/school or outwith school at some point in their lives. The remaining 10 children (12%) had either not been involved in any intervention, their parents were not aware that they had been involved, or they did not specify that they had been.

In terms of continuity of approach between home and school, only 6 of the 41 children currently involved in named interventions outside school were involved in the same intervention at school.

The number of different interventions that children were currently involved in, either at school or outwith, were pooled and are shown in table 3.17. When both the home and school environment were considered, a total of 34 (40%) of the 84 children were involved in more than one approach concurrently.

Table 3.17: Total number of interventions children were currently involved in and out of school

No. of interventions	No. of children (%)
0	20 (24%)
1	30 (36%)
2	22 (26%)
3	7 (8%)
4	5 (6%)

**3.4.14 Use of the Son-Rise Program**

As table 3.5 shows (table of current usage – page 59) the SRP was currently being used by 4 families. Although this is a small figure it means that Son-Rise is used by approximately 1 in 10 of all families currently using a non-school based intervention and 1 in 20 of all respondents. It had previously been used by 3 families, meaning that a total of 7 families had experience of the SRP, 1 in 12 of all respondents.

As table 3.18 shows, the uptake of the SRP has increased somewhat over recent years. No family had used the SRP prior to 1993, and it was only in 1998 that the numbers of families using it increased, although numbers involved remain small. However, a further 6 families indicated that they planned to begin an SRP: 4 in the coming year, and 2 at some unspecified future date.

Table 3.18: Number of families beginning the Son-Rise Program each year

Year	No. Families
1993	1
1994	0
1995	0
1996	1
1997	0
1998	4

N.B. One other family had previously used the Son-Rise Program, but dates of usage were not given.

Only 3 families had finished using their SRP. One family had used the program for 1 year, one for 3 years, while the remaining family had not specified dates. The average age of children when they began an SRP was 4 years. 4 of the 7 children who had been involved in the SRP had a diagnosis of autism, 2 of autism with learning difficulties, and one of autistic tendencies with learning difficulties.

### 3.5 Discussion

There has been little previous research in the area of non-school based interventions and consequently a lack of information on how many families are involved in the wide range of intervention approaches currently ‘out there’. This study found that 49% of children were currently involved in non-school based interventions, with 65% having had some involvement with such therapies at some point in their lives. This is quite a large proportion and indicates that non-school based interventions play a significant part in the lives of children with autism and, as such, merit further research.

Jordan and Jones’ (1996) survey found 38% involvement for school and non-school based interventions combined – much lower than the figure of 76% found in this study. One explanation for this may be that uptake of interventions has increased since the Jordan and Jones study, although this can only partially explain such a large increase over only a few years. Another reason may be related to the finding in this study that younger children were more likely to be involved in interventions than older children. Differences in age profile between the samples may explain the difference in intervention uptake; the Jordan and Jones’ sample included children over the age of 18 years, whereas this was restricted to children 18 and under.

The study reported here found that speech and language therapy was the most common form of intervention in current use, followed by music therapy, diet and the SRP. Evaluations of these interventions are therefore research priorities. As described in Chapter 1, however, it is important that such evaluations are not carried out until it is clear which types of children the

intervention is being used with, how it is being used in terms of intensity and duration, and what, if any, other interventions are being used concurrently. This groundwork is essential if evaluations are to accurately reflect use of interventions in the 'real world'. Such issues are considered in relation to the SRP later in this thesis (see chapter 5).

Unlike research in the USA, this study found use of pharmacological treatments to be very rare. The recent introduction of the hormone secretin as a treatment for autism since data collection for this study may mean though that the pattern of use of pharmacological treatments would be different if a similar study were to be conducted in the future. It was reassuring to find that there were no interventions in current use which had already been shown by research to be unhelpful, such as holding therapy or patterning. This suggests that there are effective channels of communication, in this respect at least, between those conducting evaluative research on interventions for autism and intervention providers.

Therapist-based interventions were the most common form of approach used with children with autism. 'Mid' and 'high' parent-involvement interventions were less common, although they were used by over a quarter of families involved in interventions, and by 13% of the whole sample. The predominance of therapist-based interventions does not, though, imply that children were receiving minimal parental input in the home, simply that the strategies that parents use with their children may be more intuitive rather than deriving from any named intervention approach. The comments some parents made on the questionnaire confirmed this, with a number describing individual techniques, rather than a whole intervention approach, which they had found helpful with their child:

*"I believe a strict adherence to any one method or number of methods would have been harmful and counterproductive. What has worked for our son has been an intuitive awareness of his inner world and a commitment to put his needs first, with the result that he is now venturing out of his autistic world. His steady progress and overall achievements have far exceeded my expectations!...For our son significant/secure relationships have been more important than methods."*

The majority of children were involved in only one non-school based intervention, with only 13% experiencing a combination of approaches. However, if both home and school environments were considered together, 34 (40%) of the 84 children were involved in more than one approach concurrently. This suggests that, as in the States, there may be inherent problems with the little evaluative research that is conducted, as a combination of approaches makes it more difficult to establish causal links between intervention and behavioural change in the child (Prizant & Rubin, 1999). Methodologies need to be employed which minimise this difficulty, and the question of how well specific interventions work together when used concurrently also requires further investigation. It is likely that

compatibility will depend on the ethos and theoretical background of the specific interventions being used together. For example, if two child-led interventions are being used together these could well be compatible, even if the techniques used in each are somewhat different. Only 6 of the children proved to be involved in the same intervention both at school and at home, but it may be that other children, although involved in different interventions in the two environments nevertheless have a continuity of overall approach since a number of different interventions have developed from a broadly similar theoretical base.

In terms of changes over time, the use of non-school based interventions did seem to have increased; significantly more children born 1993-1996 had had experience of such interventions than those born before 1993. However there is an alternative explanation for this finding. One is that this kind of intervention use has not truly increased in recent years, and that the result is an artefact of the type of children included in the sample. Children with milder autistic spectrum disorders tend to be diagnosed later in life (Howlin & Moore, 1997). It is possible therefore that children in the 1993-1996 group have more severe forms of autism than those in the pre-1993 group, and that children with less severe forms of autism born post 1993 would not have been diagnosed by the time of data collection and so would not have been included in the sample. If the 1993-1996 group had a greater proportion of children with more severe autistic spectrum disorders, it would not be surprising to find higher intervention uptake rate than in the pre-1993 group, as this group would more obviously require intervention.

Inspection of diagnoses patterns suggest that the younger sample (born 1993-1996) did indeed contain a smaller proportion of those with mild forms of autistic spectrum disorder than the older sample. For example, only 1 in 24 had a diagnosis of Asperger syndrome in comparison to more than 1 in 4 in the older sample. However, the Asperger group did not, in fact, have a particularly low rate of intervention use (12 of the 18 children with Asperger syndrome had been involved in non-school based intervention at some point in their lives), suggesting that although there are differences in types of autistic spectrum disorder between the two age groups, this is not the source of differences in intervention uptake.

It is, therefore, not possible to establish with certainty whether uptake of interventions has truly increased over recent years or whether this is an artefact caused by the type of family in the post-1993 sample. To conclusively answer this question, this study would need to be repeated at a later date, with the addition of a representative sample of all post-1993 children and their families surveyed.

There are several possible explanations why uptake of non-school based interventions might, however, have been expected over recent years. The first is that such interventions now receive much wider publicity, on TV and on the internet. As the number of families using the internet has increased in recent years, information about autism interventions has potentially become much more accessible. The fact that some of the more recent literature on autism for parents contains references to websites of relevant information (e.g. Trevarthen *et al*, 1998; Cohen, 1998) suggests that this route to information is now in common usage.

Another reason for the apparent increased uptake of non-school based interventions may stem from the fact that there are now more children being diagnosed with autistic spectrum disorders. Families may therefore be more likely to know other parents with a child with a similar diagnosis, and hence be more likely to find out about interventions by word of mouth. There has also been a shift in power away from professionals towards parents, with the notion of 'parent partnership' becoming more common. Parents may now feel more able either to use interventions themselves or to work in partnership with a therapist, and may feel more confident in requesting therapist-based interventions for their child outwith the more traditional school setting.

Such explanations emphasise Bronfenbrenner's (1979) viewpoint that what goes on within the family, in this case the parent's decision to use an intervention with their child, cannot be viewed in isolation from the society in which the family live.

In terms of the four types of intervention identified earlier in this thesis - 'high' and 'mid parent' involvement, 'therapist-based', and 'non-interactive' - therapist-based interventions have remained the most common, but the other types would appear to have become more prevalent over recent years. Ideally this study should be repeated with a larger sample to confirm the trends identified here. The finding could reflect either a difficulty in obtaining therapist-based services or an increased availability of information on these alternative forms of intervention. Although 'mid' and 'high' parent involvement interventions remain less common than therapist-based approaches, usage of them does seem to be increasing. Over a quarter of the 41 children currently involved in interventions were participating in approaches in which parents had taken on the role of therapist. This suggests that examination of the effects on the family of parent involvement in intervention will be a fruitful area for future research. As suggested in Chapter 2, areas such as the effect on siblings, parent stress, and financial implications are all possibilities for further inquiry in relation to 'mid' and 'high' parent involvement interventions. These are considered in relation to the SRP later in this thesis.

The proportion of interventions used which were classed as 'local authority funded interventions' was found to have decreased over time whereas the proportion of 'privately funded' interventions has increased. This could be because a greater number of families are seeking help from health and educational services, so resources available to support individual families are diluted (Rogers, 1999). Parents may therefore have no alternative but to seek privately-funded interventions. The views expressed by some parents confirmed a difficulty in accessing satisfactory levels of statutory services:

*"We have asked for speech/language therapy and social skills help but were told only very severely affected children get speech therapy and have been waiting for 4 months for news of the social skills course - we find it all very frustrating."*

*"As parents we have been left to devise our own methods and approaches with little guidance from health authorities. As a result we feel disenfranchised and can only marvel at our son's progress to date... That he is expected to learn without professional help is a sad testimony to the disorganisation of the health and education services."*

*"Any intensive work done by a specialist I feel would help our son - I have repeatedly asked for help and have not had any except for ability tests with no follow up treatment about two years ago."*

Despite the difficulty some parents experienced in accessing local authority funded services, a number of parents who had been involved in such interventions commented that they had found them invaluable. Data from this sample also indicated that children tend to begin local authority funded interventions at a significantly earlier age than those beginning privately funded ones and so, for many families, the interventions supplied by the local authority will be the first source of autism-specific help. Provision of speech and language therapy for many families often begins even before formal diagnosis. It seems probable that for some families the assessment by the speech and language therapist at this stage has an influence on the efficiency and accuracy of later diagnosis.

For families beginning interventions after diagnosis, this happened on average 10 months after diagnosis. Families may therefore be seeking information on interventions from professionals working with their child just before this time. However, there was great variation between families and it cannot be assumed that all families will be ready to receive information at the same time.

In this study the exploration of links between the child characteristics and level of intervention involvement was limited by the small numbers of children involved in each kind of intervention. One finding was that the children involved in non-school based interventions were significantly younger than those who were not involved. There are several possible explanations for this. Firstly it may be related to the belief that interventions

are more likely to be successful with younger children, perhaps making parents and professionals more likely to implement interventions with younger children. Secondly, it may be easier for parents to access services such as speech therapy in the years immediately after diagnosis, e.g. parents may be referred straight on to speech and language services. A number of families may also be offered speech and language therapy before a diagnosis is made, again contributing to a trend towards intervention involvement at younger ages. Another possible reason is that parents may feel more motivated to seek out interventions while their child is young, and have more opportunity to do so if the child is not of school age. They are also perhaps less likely to be working when their children are younger and so have more time to get involved in interventions. This questionnaire did not request information regarding employment and so it is impossible to investigate this further. This aspect is explored further in relation to the SRP in Chapter 5, however.

No diagnostic group was noticeably different from other groups in terms of level of intervention use: around two-thirds of each diagnostic group had been involved in non-school based interventions at some point in their lives. This perhaps reflects that many of the interventions, such as speech and language therapy and music therapy, may be suitable for all children with autistic spectrum disorders, regardless of specific diagnosis. Another possibility is that it indicates that the decision to use an intervention is more related to the availability of services and parents' own views on interventions, than to the child's diagnosis.

The specific focus of this thesis is the SRP. This study confirmed that although the number of families using this approach was small, it was nonetheless relatively common in comparison to other interventions, with numbers involved increasing. One in ten of all families currently using non-school based interventions were using this approach, with numbers likely to more than double over the coming year. Along with music therapy, the SRP was the intervention that families were most likely to consider using at some point in the future, but the small number of children currently involved made it difficult to identify a characteristic profile of children with whom the approach is used or typical length of use. A survey of a larger number of children involved in the SRP was therefore undertaken to explore these issues, and is reported later in this thesis, in Chapter 5.

While this study has established a number of relevant trends in relation to the use of non-school based interventions, there are a number of factors which somewhat limit the extent to which the results from this study of Lothian families can be generalised to other families with children with autism. Firstly, there was not a 100% response rate, and it is reasonable to assume that parents involved in interventions would have been more likely to reply than those who were not. Some parents who were considered to be under considerable stress were

also not sent questionnaires. Although it cannot be established, these parents may have been less likely to be actively involved in non-school based interventions, and if included in the sample it would have decreased the overall proportion of families involved in such interventions. Another limitation on generalisation relates to the fact that the children of parents returning the questionnaire were on average younger than those of parents who did not. Given that younger children were found to be more likely to be involved in an intervention than older children, level of intervention use across the wider population is likely to be lower than the results from this study suggest. Yet, even with such factors taken into account, use of non-school based interventions is likely to affect a sizeable proportion of families with children on the autistic spectrum, and as such merits further investigation.

It also has to be noted that this study was carried out in a largely urban area of Scotland. There may be inherent differences between urban and rural regions which affect intervention uptake: in urban areas there may for instance be a greater availability of information on interventions, greater opportunities for contact with other parents to discuss and share ideas about interventions, and more people to draw on as helpers to run intensive programs such as Lovaas and Son-Rise. There may also be differences in uptake of interventions between different parts of the UK. Jordan and Jones (1996) note anecdotal reports of a lower uptake of alternative approaches in Scotland than in England and Wales, and suggest that this may reflect either a greater satisfaction with, and trust of, the educational system in Scotland or perhaps a lower level of media publicity for interventions in Scotland. On the other hand, it has been found that children in Scotland tend to be diagnosed slightly earlier than children in England (Howlin & Moore, 1997). As younger children tend to be more likely to be involved in interventions, the high uptake of non-school based interventions identified in this urban area of Scotland may not be equaled in similar urban areas in England. A nationwide study would be the only way of establishing whether the patterns found in this study were similar to those in other areas.

Given the overall trends found in this study of Lothian families, it would seem useful to repeat this survey using a larger number of participants spread over a wider geographical area. This would permit the links between child characteristics and intervention uptake to be explored in greater depth, as well as allowing the use of statistical analysis to test the significance of trends identified here. Repeating the study at a later date using the same population would also be advantageous as it would allow investigation of whether uptake of non school-based interventions has truly increased over recent years, or whether the finding here was skewed by the particular children included in this specific sample.



It would be advantageous in any similar future study to ask specific questions about the level of parent involvement and funding arrangements for the various interventions that families use, in order to confirm the trends found here. In this study the interventions were analysed using a predetermined categorization system based on how they are typically described in the literature at present. The validity of similar studies in the future would be increased if parents were asked directly about this, although care should be taken as this may increase the questionnaire length which in turn is likely to decrease return rate.

Such an expansion would though allow exploration of the extent to which parents use interventions as they are commonly described. For example, there is uncertainty over the extent to which parents use 'high-parent involvement' interventions as intensively as they are frequently described in the literature. It seems likely that some parents at least will adapt aspects of intervention delivery, such as intensity, to suit their own child and family circumstances, something which will be further explored in relation to the SRP in Chapter 5.

This first study has shown that parent involvement in interventions is relatively common in families with a child with autism, with both intensive programs like Son-Rise and less intensive approaches such as Hanen and TEACCH being used by families in Lothian. The following chapters examine issues surrounding parental involvement in more detail, focusing specifically on the SRP.

## CHAPTER 4

# THE SON-RISE PROGRAM INTERVENTION FOR AUTISM

### 4.1 Introduction

Study 1, described in the previous chapter, found that among the wide variety of interventions for autism currently in use, the Son-Rise Program is becoming increasingly common. The remainder of this thesis will focus on this specific intervention, exploring in particular issues surrounding family involvement and the prerequisites for any evaluation of its efficacy. In this chapter the history of the SRP will be described, along with its main principles, techniques, and the relationship to some of the many other interventions currently available for autism.

The Son-Rise Program is a method of working with children and adults with special educational needs, a large number of whom are children with autism. It is an interactive approach which emphasises the importance of developing a relationship between the child and their parents. Fundamentally, it is a child-led therapy which aims to accept the child as he or she is and then to encourage (but not push) the child to develop and to become more interactive. The SRP is a 1:1 home-based therapy, usually carried out in a specially designed playroom by the parents of the child with the help of a team of volunteers.

The techniques in the SRP stem from the Option Process<sup>1</sup>, a personal growth approach designed to help people lead happier more accepting lives by exploring and challenging their negative beliefs. This was first put forward by Bruce Di Marsico in the 1970s and was known as 'The Option Method' (Evans, 1989). It was then developed and described in a number of books by Barry Neil Kaufman (e.g. 1977, 1991). Part of the Option Process includes exploration of beliefs in a non-judgmental discussion known as an Option Process Dialogue.

### 4.2 History of the Option Process and the Son-Rise Program

The Option Method was created by an American psychotherapist, Bruce Di Marsico, in the early 1970s, in response to analysis of his own negative experiences in a social situation (Evans, personal communication). He told of being at a party and noticing he was angry with himself for feeling shy. He thought to ask himself why he was angry, and realised that it was

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<sup>1</sup> The Option Process is a registered trademark

because he wanted to be more extrovert. He then asked himself why he believed that being angry with himself would help him become more extrovert and, using these questions, began to explore the connections between his beliefs and his emotions. He later used this method of questioning with his psychotherapy clients to explore the beliefs behind their unhappiness. From this, the Option Method developed as a therapeutic approach to personal growth. Di Marsico trained a number of students in this method, including Barry Neil Kaufman.

Kaufman and his wife Samahria adapted and modified the Option Method to form the Option Process which they taught to adults. Later, when their son Raun was diagnosed with autism, they used the philosophy of the Option Process to form techniques for working with him on a 1:1 basis; this method was later named the Son-Rise Program.

The Kaufmans worked with their son in the non-distracting environment of their bathroom, 12 hours a day, 7 days a week, for 3 years (Kaufman, 1994). They judged their work to be a success as Raun went on to graduate from an Ivy League university, has a “near genius IQ”, and shows no residual signs of autism (The Option Institute and Fellowship, 1998). As a result other families asked them to work with their special needs children and due to parents’ demand for training, the Option Institute and Fellowship was founded in 1983 in Sheffield, Massachusetts (Kaufman 1981, 1994). It is a non-profit organisation which teaches both Option Process personal growth programs and the SRP.

The SRP is taught for use with children and adults with a variety of special needs. These include those with autism, attention deficit disorder, pervasive developmental delay, brain impairment, Asperger syndrome, Rett syndrome, multiple sclerosis, cerebral palsy, mental retardation, epilepsy, and any other neurological or muscular disorders (The Option Institute and Fellowship, 1996/97).

### **4.3 Principles of the Option Process**

The Option Process is based on Di Marsico’s principle which states that how we behave and feel is determined by our beliefs, which we can examine and choose to change, if we wish, for more positive beliefs. The key points are:

#### ***Happiness is a choice***

It is proposed that rather than external events having the power to make us feel happy or unhappy, it is the way we choose to view these events that determines how we feel. For example, if you are made redundant from your job you could choose to see this as negative,

as it means you will have less money and you think that you inadequate. Or you could view it in a positive way, as it means you now have a range of new career possibilities available to you. Either way it is not the redundancy itself that has determined how you feel, but your beliefs about the situation - how you choose to view it. You can make a conscious choice to be happy about any given situation.

*"Our feelings are not products of external events. They are determined by internal events - our judgements, interpretations, beliefs and decisions."*

(The Option Institute and Fellowship, 1998)

### ***To love is to be happy with***

This is the view that if you love another person you are happy with them exactly as they are, and you accept them as they are. This stems from the idea that 'happiness is a choice' - a person may not be exactly as you would wish them to be but you can choose to be happy about this situation.

### ***Needing is not the same as wanting***

Kaufman states that you can still want a person to change, although you are happy with them exactly as they are. While this appears a paradox, Kaufman points out that there is a difference between wanting and needing. From the Option perspective although you may want another person to change you do not need them to change, in order to continue loving and being happy with that person.

*" In wanting, my happiness is not contingent on getting. But in needing, I give my wanting extra importance by making my happiness dependent on getting."*

(Kaufman, 1977)

While these are the key points of the Option Process, there are a number of further, related principles:

### ***We are all trying our best***

Kaufman (1977) believes that everyone behaves in the best way they can, in accordance with their current beliefs and understanding of situations.

### ***You do not have to use unhappiness as a motivator***

Kaufman (1991) states that many people believe that if they are not unhappy about a situation then they will not try to change it. He disagrees with this and believes that being happy makes us more effective and more likely to change a situation.

### ***You are your own best expert***

Kaufman does not believe that we should turn to professionals to help us become happier, because in doing so we take on their interpretations of our beliefs. Instead, in the Option Process, you explore your own beliefs and choose which to continue to accept or discard: your own interpretation is the only one that matters.

## **4.4 Option Dialogues**

An Option Process Dialogue is a method of asking questions of another person to help them explore their system of beliefs. Each question is asked with a non-judgmental attitude and solutions to problems are not offered by the person asking the questions (in following with the idea 'you are your own best expert'). The goal of an Option Dialogue is to help another person explore their beliefs which are affecting their feelings and behaviour and, if they so desire, change the beliefs that make them unhappy (Evans, 1989; Kaufman, 1979).

## **4.5 Principles of the Son-Rise Program**

The Option Process principles described above underlie the SRP. In addition to these the SRP places special emphasis on a number of related principles when working with children with special educational needs (Levy, 1999; The Option Institute and Fellowship, 1996/97).

### ***The importance of a loving and accepting attitude***

It is the view of the Option Institute & Fellowship that, while they teach a number of important techniques for working with children, these techniques are ineffective without the attitudinal foundation 'to love is to be happy with'. This accepting attitude means that the parent does not judge the child's behaviour as good or bad, appropriate or inappropriate, but recognises that the child is doing the best he or she can. The Option Institute stresses that children with special educational needs can very readily pick up on the attitudes of others:

*"We have noticed over and over again that nonverbal children rely on their ability to pick up attitude "transmissions" even when the initiator camouflages his or her discomfort with smiles." (Kaufman, 1991)*

### ***The gift of a special child***

Parents are encouraged to choose happiness and, rather than viewing their child's difficulties as a stressful catastrophic event or as a burden to be coped with, to see it as a gift.

### ***The parent is the child's best resource***

Although professionals are acknowledged as being well intending and providing meaningful assistance, the Option Institute feel that because a parent has more knowledge of, more love for, and more interest in their child than any professional, they are the most ideally suited to run the SRP for their child.

### ***The child as teacher***

The SRP is a child-led approach. This concept, introduced in Chapter 2, covers a range of interventions, including Intensive Interaction. Although all of these interventions aim to help the child develop skills such as social interaction and communication, the focus is not on specific goals which the child must achieve, as would be the case in more directive, adult-led approaches such as the Lovaas approach. Instead the emphasis is on joining in with the child's choice of activities and interests, even if they are not socially acceptable behaviours. By joining in the adult can develop rapport with the child and then, when the child is engaged, develop the interaction. This concept will be discussed in greater detail later in the chapter.

## **4.6 Techniques in the Son-Rise Program**

### **4.6.1 Overview**

Within this child-led intervention there are two groups of techniques used. These are "bonding through acceptance" and "inspiring growth" (The Option Institute and Fellowship, 1996/97).

'Bonding through acceptance' is used at times when the child is less interactive and their behaviour is characterised by stereotypic movements, echolalia, or repetitive routines (fig 4.1). It is the child-led, non-directive side of the approach where the adult joins in with the child's activity or behaviour, rather than requesting anything of the child. The adult focuses on showing and feeling complete acceptance of the child and tries to be non-judgemental of their behaviour. The goal of 'bonding through acceptance' is:

*"to develop a deep rapport (trust, comfort, acceptance, love and enjoyment) with that special person. Once this has been established and the child or individual is indicating a certain degree of attentiveness, curiosity and interest in interacting with you, your intention shifts to inspiring growth. At this point you ask for more from them and challenge them, still from the most accepting and fun-loving attitude, to help them fulfil their greatest potential."*

(The Option Institute and Fellowship, 1996/97).

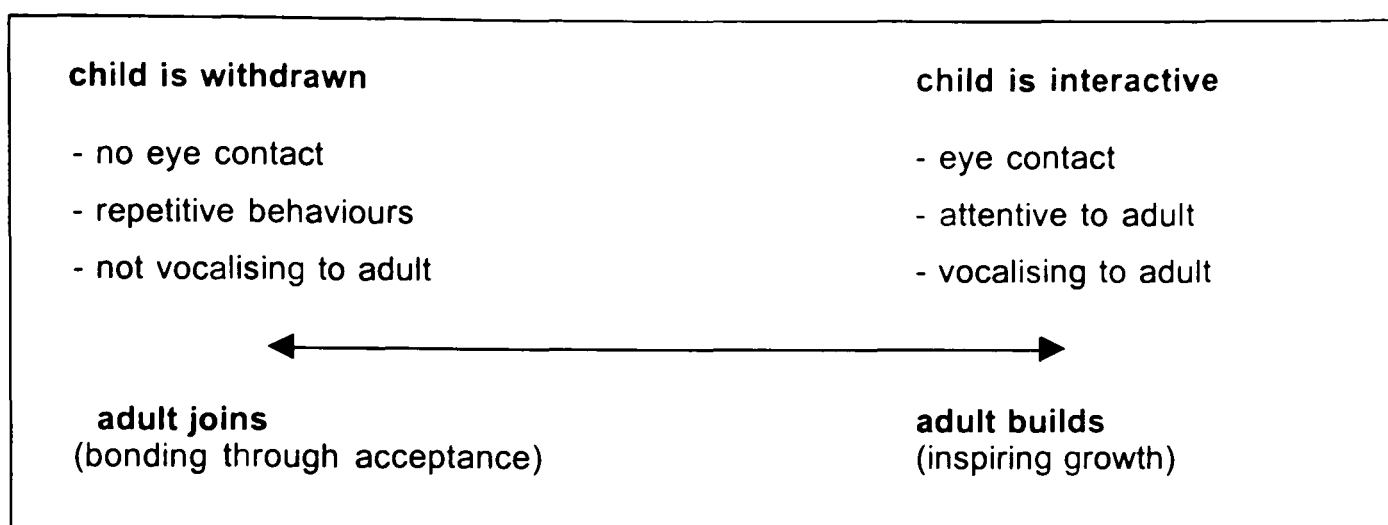


Figure 4.1: Times to ‘bond through acceptance’ and times to ‘inspire growth’

‘Inspiring growth’ is, by contrast, more directive on the part of the adult. Here the adult can initiate activities, extend an activity that the child is already involved in, or make a request of the child. However ‘inspiring growth’ is still child-led in that if the child indicates that they do not wish to comply with the adult’s initiation/extension/request, then the adult should be respectful of this, and continue to follow the child’s lead, or make a different request.

The techniques involved in both ‘bonding through acceptance’ and ‘inspiring growth’ are applied within the context of the positive and accepting attitude described in the previous section.

#### 4.6.2 Bonding through acceptance – the techniques

‘Bonding through acceptance’ can be shown in the following ways:

##### *Imitation (or ‘joining’) of stereotypic behaviour*

In imitation of the child’s ‘isms’ (the Kaufmans’ word for stereotypic behaviour), repetitive routines and echolalia the adult does not simply copy the child’s behaviour, but does so sincerely and enthusiastically, showing that they accept the child’s behaviour. The imitation is also a way of encouraging the child to make solitary play into two person play (The Option Institute and Fellowship, 1996/97). In cases where the adult feels that they cannot join in completely with the child’s stereotypic behaviour (for example if it involved self injurious behaviour), they are still encouraged to try to accept the behaviour and not view it negatively.

Imitation of the child may be the first step in an SRP as it was with the Kaufmans' own program with their son:

*"We began by imitating him on a global scale - not just as a strategy or tactic, but sincerely being with him; rocking when he rocked, spinning when he spun, flapping when he flapped."* (Kaufman. 1979; 20)

The Option Institute state that, rather than reinforcing the stereotypical behaviour, this imitation will help to establish a connection between the adult and child, and ultimately result in a decrease in stereotypical behaviour (Levy, 1999).

### ***Joining with child's choice of activity***

The adult joins in with what the child chooses to do, again as a means of conveying acceptance of the child, and of encouraging the child to turn the activity into a two person game. This does not mean that the adult cannot suggest other activities, or extensions to the child's own activity (see 'requesting' under 'Inspiring growth,' below).

### ***Maintaining a non-judgemental attitude***

As previously mentioned, the adult's accepting attitude towards the child is the most important part of the SRP. No behaviour by the child is regarded as 'bad' or 'inappropriate'. The child should never be told not to do something (although certain extreme behaviours can be ignored). This is not to say that all the child's behaviours are considered to be ultimately desirable, simply that the adult recognises that the child is currently doing the best he or she can.

## **4.6.3 Inspiring growth – the techniques**

At times when the child is less withdrawn and is showing more attentiveness towards the adult (even momentarily), the adult shifts to trying to challenge the child more. Techniques include:

### ***Building***

The adult tries to expand the activity which the child has already chosen by adding some variation to it. In this way the adult can teach the child something new, or develop their flexibility by changing a routine game. The adult uses energy, excitement and enthusiasm to make the extension a compelling choice for the child, and builds on the current task a little bit at a time, to make it manageable for the child.



### ***Requesting***

Here the adult asks something of the child or tells him or her to do something. Again, ideally this will be related to the child's activity at that time, so that the child is motivated to comply with the adult's request. The adult could request that the child makes eye contact, uses language, shares a toy - anything that will stretch and challenge the child. Again the adult should make the request in a way which is inviting for the child.

### ***Initiating task selection***

When the child is not involved in an activity, the adult can take the lead and initiate an activity.

As with 'bonding through acceptance', the adult's attitude is the most important part of the 'inspiring growth' techniques; they must show acceptance of the child's choices. This means that if the child indicates, through word or gesture, that they do not wish to comply with the extension, request, or initiation, then the adult must respect the child's wishes. However, the adult can try the request later on, again at a time when the child is attentive to the adult.

The adult should truly believe that the child will ultimately achieve what is being asked of them, even if they have failed many times in the past. Kaufman states that belief in the child will affect the way in which the adult makes their request, making it more likely that the child will succeed. Due to this belief, the adult is encouraged to be persistent with their requests (except where the child has indicated that they do not wish to comply with the request), but it is stressed that this must be done in a fun and loving way.

#### **4.6.4 Additional Techniques**

In addition to 'bonding through acceptance' and 'inspiring growth' there are a number of other techniques in the SRP:

#### ***Energy, excitement and enthusiasm (the 3 Es)***

The adult shows these qualities using voice, facial expression and body language. However, it is not necessary for the adult to be constantly loud and shouting; variation is seen as important in keeping the child interested in the adult as an interactive partner.

By using 'the 3 Es' the adult attempts to show that:

- they take delight in everything the child does  
(no matter how many times he or she has done it before)
- people are fun to interact with

- they are still excited even if the child can't reach their goal/complete an activity – this way the child will be encouraged to try again
- they believe that the child will succeed in, and have fun doing, what has been requested of them, making the child more likely to try.

### ***Eye contact***

In the SRP it is seen as very important that the child develops good eye contact as it will help them to interact and learn. The adult can encourage eye contact in several ways. Firstly they can ask for it in a fun way - especially as part of a game where the child gets something out of it (e.g. "Look at me and I'll chase you!"). They can also respond to any eye contact from the child with praise and position themselves facing the child, at or below their eye level, to make it easier for them to make eye contact. Finally, adults are encouraged to hold food and toys next to their own eyes before giving them to the child.

### ***Being clear***

The adult is encouraged always to be very clear in all communications with the child. This is because it is thought that if the child already finds the world somewhat confusing, it is helpful for them to know exactly how the adult feels, or to be sure of what is being asked of them.

### ***Praise***

The adult tries to show a positive and enthusiastic response to everything the child does in order to demonstrate that they appreciate and accept the child's actions. The idea is that initially this will give the child motivation to do things, and after a while they will become self-motivated, doing tasks for their own pleasure, rather than to get a big reaction for doing it. The child should be praised for their own actions, as well as for attempting to achieve a goal which the adult has set – even if they are not successful. The child can also be praised for refusing to comply with the adult's request, as this shows that the child is attempting to communicate their desires. Behaviour that the parent may want to discourage, such as spitting or violence, can be ignored or a similar but more acceptable behaviour suggested.

### ***Responding to requests***

The adult tries to respond very quickly to the child's requests for toys and activities. This way the child learns that it is worth their while communicating and interacting with people because it has immediate concrete results (e.g. getting toys, playing games), which in turn should increase the child's motivation to interact. For the same reason the adult tries to be

equally responsive if the child says “No!” The exception to this method of quick response is if the child has the ability to vocalise, and cries. In this case, the adult tries to maintain their accepting attitude but responds much more slowly, seeking to encourage the child to use vocalisation, gestures or another means of communication as an alternative to crying. If the child does then use language or gesture, the adult responds very quickly to the child’s request. The aim is to teach the child that crying is not the quickest and most effective way to get a positive response to their request - language is.

### ***Being present***

While working in the Son-Rise Playroom, the adult tries to focus themselves on the present moment. There are several reasons for this. Firstly, it helps the adult be much more attentive towards the child and their work with that child. Secondly, it helps the adult feel comfortable and happy with the child.

In implementing all these techniques it is imperative that the adult never physically manipulates the child against their will, as this goes against the central principle of the program: that you accept the child’s choices.

## **4.7 The Son-Rise Program – additional features**

### **4.7.1 Therapeutic environment**

The concept of the playroom is central to the SRP:

*“Working with your child in a playroom enables you to eliminate distractions such as siblings, television, loud music and other distractions that exist in the rest of the house. The playroom also gives your child a “safe” place to learn, where you don’t continually have to say “No!”*

*(The Option Institute and Fellowship, 1996/97)*

The Son-Rise manual recommends that the playroom is designed to be as non-distracting as possible in order that the child’s focus of attention is more likely to be on the interaction with the parent/volunteer than on their surroundings. For this reason it is suggested that the floor is covered with plain coloured linoleum, the walls are a plain colour, the window is covered with rough Plexiglas, and there are no televisions, tape recorders, or computers in the room. The room should also be free of potential dangers and breakable objects, such as ornaments, unlike the rest of the house and the outside world. This means that the adult can be accepting of all the child’s activities, knowing that it is a risk-free environment.

A major feature of the playroom is the placement of toys on shelves on the wall, which are outwith the reach of the child. This is so the child has to ask the parent or volunteer for them, creating a motivation to learn to point or use words and to interact with the adult, as immediate and concrete results (getting toys) come from learning these skills. In addition to the toys on the shelf, many parents also put larger items in the room, such as a table and bench, a slide, a large inflatable ball, or trampoline. However, it is important that the room is not cluttered, and that toys are put back on the shelf when they are not being used so the child can maintain focus on the adult and the game in hand. The room normally has a two-way mirror in the door, which allows volunteers to be observed working with the child.

As with the rest of the SRP, attitude is the most important feature related to the room. The adult's attitude towards the room helps determine how effective they are when they are in it with the child, and also how the child responds to the room. If the adult views it as a fun and educational environment for the child, rather than somewhere their child is forced to stay for a set number of hours per week, it is more likely that the child will enjoy being in the room.

The playroom is designed to offer the child total control, although the one factor that the child does not have potential control over is when they can leave the playroom.

#### **4.7.2 Training**

There are two methods of initial parent training in the SRP:

##### ***The 'SRP Intensive'***

This is a one week individualised course at the Option Institute. During this week parents are able to watch and learn from the Option staff working with their child. Parents themselves are also observed interacting with their child using the SRP and given feedback and guidance to develop their skills. They are given the opportunity to take part in Option Process Dialogues to explore feelings which could inhibit their effectiveness as their child's therapist, and are taught how to use this process with the volunteers in their program. Parents also learn how to record their child's behaviour and progress in order to adapt the program to suit their child's stage of development and how to run group meetings for their team of volunteers. Advice is given on how to create an SRP playroom in their own home and how to recruit and train volunteers. At all times during the week where the parents are not themselves being observed interacting with their child, their child is interacting with the staff at the Institute.

### ***The 'SRP Start-Up'***

As the SRP Intensives places are often fully booked as much as two years in advance, the Option Institute developed the SRP Start-Up course. This is a 5-day course taught to a much larger group of parents and professionals (up to around 200). The children do not attend, but parents are taught many of the same techniques covered in the Intensive course, although obviously without the same degree of individualised attention and direct feedback on their own child. Courses are held at the Option Institute, and a number of other locations, including London.

In recent years, parents have tended to attend the Start-Up and begin their home-based program while waiting for an opportunity to attend the Intensive course. Parents attending these initial training courses are given a manual covering the main points of Son-Rise and its philosophy and techniques, along with advice on practicalities such as creating a playroom and training volunteers.

### ***The SRP Maximum Impact Advanced Training Program***

This course is designed for parents who have begun running their home-based SRP and have attended either the SRP Start-Up or the SRP Intensive. This 5-day course is designed to help parents plan the next stage of their SRP, learn techniques to keep themselves and their volunteers motivated, and gain more confidence in using the Option Dialogue process.

#### **4.7.3 Support Services**

After the initial Intensive or Start-Up training, parents are subsequently offered follow-up support:

- (1) Phone Consultation - 50 minute discussion of any aspect of the SRP.  
(\$75.00 - 125.00)
- (2) Phone Dialogue - an Option Process Dialogue with a member of the Option staff.  
(\$75.00 - 125.00)
- (3) Video-Feedback - Option staff review a videotape of either the parent or a volunteer working with a child and then give feedback over the phone (or via audiocassette)  
(\$140.00 for 80 minutes of staff time spent reviewing and giving feedback)
- (4) Feedback Training - parents can send a video or audio cassette tape of themselves giving feedback to one of their volunteers, and receive feedback on this.  
(\$140.00 for 80 minutes of staff time spent reviewing and giving feedback).
- (5) Outreach Program - an Option teacher will visit the parents' home, evaluate their program, and give training to the parents and the volunteers. However, these

programs are offered subject to availability and locality and opportunities for them tend to be limited.

(Indicative charges are given based on 1998 costings. These are fees payable to the Option Institute & Fellowship, and are in addition to the cost of the international phonecall).

It is recommended that parents use follow-up support in the form of phone consultation or video-feedback every other month (The Option Institute & Fellowship, 1996/97).

#### **4.7.4 Volunteers**

Families, especially those running full-time programs, may choose to use volunteers to assist them. It is recommended that parents spend the first month or two working by themselves with their child, so they have time to become comfortable with using the SRP before training volunteers. Volunteers can be any age and from any background, although many parents do tend to recruit from universities, as students are often quite flexible time-wise. It is recommended that parents first give applicants a number of Son-Rise books to read so they can learn the principles. They should then watch the parent working with the child, and following this, work for a short period (about 15 minutes) with the child and be given feedback by the parents. As the volunteer gains experience, the session with the child can become longer, increasing to two hours, and the feedback less frequent. Families vary in how many hours they ask the volunteers to work with their child each week, but 4-6 hours is recommended as this gives volunteers the time to develop a relationship with the child.

It is recommended that group meetings are held for all of the volunteers at least once a fortnight for 2 hours. The aim of these meetings is to review the child's progress, come up with solutions for any difficulties that have been experienced in the playroom, plan goals for the next fortnight, and ensure that the motivation of all those involved is maintained.

#### **4.7.5 Intensity and concurrent school attendance**

The Option Institute and Fellowship recommend giving the child as much 1:1 SRP time as possible each week. However, this must be balanced with the parent only doing as much as they feel able to, as they will be far more effective working with the child for a short time when they actually want to, rather than for a long time when they feel they are supposed to.

In terms of running the SRP with school-age children, some families choose to take their child out of school in order to run a full-time program, while others use it part-time after

school and at weekends (Kaufman, S., 1998). While the Option Institute feels that it is up to the individual family to decide how intensively to implement the SRP, they do express concerns that children may receive 'mixed messages' if learning takes place in two different environments and note that schools cannot provide the intense level of 1:1 teaching that can be provided in an SRP (Archer, 1997; Jordan, 1990). While some schools do implement elements of the SRP, this tends to be part of a more eclectic approach, and it is seldom implemented on a full-time basis with any one child (Jordan & Jones, 1996; Macey, 1996).

#### **4.7.6 Outcome**

The Option Institute does not claim to offer a cure for autism (Kaufman, 1991; Kaufman, S., 1998). While some authors (Howlin, 1997, 1998a; Maurice, 1993) feel that the use of the word 'miracle' in the SRP promotional material contradicts this claim, it could be argued that the term 'miracle' refers to the change in the parent's attitude towards their child's disability as opposed to the outcome for the child. Regardless of whether the Option Institute offer a cure or not, some parents may begin this intervention with very high expectations of outcome, based on the success that the Kaufmans had with their own son, reports of which are frequently used in their publicity literature.

### **4.8 Comparisons to other interventions**

Viewing the SRP within the context of the range of autism interventions which now exist may help to clarify the most salient aspects of the approach and the ways in which it is unique.

#### **4.8.1 Similarities to TEACCH, Portage, holding therapy, patterning & Lovaas**

In terms of the environment of the Son-Rise playroom, the approach is probably most similar to TEACCH, described in Chapter 2. Both approaches stress the need to modify the environment for the child, creating a non-distracting space, although the SRP does this to a greater extent. Both also emphasizing the need for the adult to express themselves very clearly in all communications with the child. Another common aim is the need to create predictability for the child, prior to helping them become more flexible, although the two approaches differ in how this is achieved. In TEACCH it is done through visual schedules and a well-defined classroom layout (Knott, 1996). In the SRP the emphasis is instead on imitation of the child and allowing him or her to take control of their environment – techniques which Dawson and Adams (1984) suggest can enhance predictability for children with autism. In TEACCH the agenda is controlled by the adult to a far greater degree, with more focus on the achievement of pre-set goals. There are also other differences between the approaches. For example, in the child's later years the TEACCH approach places a strong

emphasis on the incorporation of vocational training which is not a feature of the SRP. Despite the similarities in their vision of an optimum environment for children with autism these two approaches, therefore, have less overlap than it might at first seem.

The SRP also shares features with a number of the other interventions described in Chapter 2. For example, like Portage and holding therapy, it is home-based. It also employs the use of video-feedback for the development of interaction methods, as does the SPIN approach. As with holding therapy and music therapy, it focuses on the development of the interpersonal relationship between the adult and child, although the way that this is achieved is radically different - holding therapy involves the use of physical manipulation which is totally against the Son-Rise philosophy of respect for the child's choices (Jordan, 1990; Loumgair, 1997). Similarities between these various interventions and the SRP extend to only one or two features, and in each case there are major differences in technique, ethos, or practicalities which mean that overall they have little in common with the SRP.

As described in Chapter 2, the SRP is also similar to patterning and Lovaas in terms of degree of parent involvement, environment (all are home-based), and the need for recruitment of helper therapists. Yet despite these similarities, the techniques of the SRP differ greatly from patterning which involves physical manipulation and a total absence of any control for the child (Jordan, 1990).

Similarities with the Lovaas approach are also restricted and theoretically the two appear diametrically opposed (Jordan, 1990; 1991). Jordan proposes that there are some similarities though, in that behavioural techniques are used in both approaches. For example, although the SRP claims to be nonjudgemental, in practice some of the child's inappropriate behaviours are ignored, as they would be in the Lovaas approach. Thus, both approaches judge the child's behaviour at some level. However, there are differences between the approaches in the attitude of the adult during the child's inappropriate behaviour. Within the SRP there is a far greater emphasis placed on the adult's continuing feeling of acceptance for the child, no matter what their behaviour. Although there is, of course, acceptance of the child within the Lovaas approach, this attitude is not emphasised to such a great extent. Another difference between the approaches, as Jordan notes, is the types of behaviour that would be ignored or redirected. For example, in the Lovaas approach stereotypical behaviour would be discouraged, whereas in the SRP it would be imitated.



Jordan (1990, 1991) also observed that both methods use material rewards and social praise to reinforce desired behaviour. In this respect, both methods are using similar behavioural techniques. Again though, there are perhaps differences in that within the SRP material rewards are more likely to be contingent with the child's activity and chosen by the child, whereas within the Lovaas approach the reward may be unrelated to the child's activity and selected by the adult. In terms of social praise, although both approaches praise desired behaviour, the SRP perhaps places greater emphasis on the need to praise the child for activities which they themselves have chosen to do, as well as ones which the adult has asked them to do. In contrast with the Lovaas approach, in the SRP the child is also praised for refusing to comply with the adult's request, as this shows the child's ability to make decisions about what they want to do and to communicate this effectively.

Another similarity between the two approaches is that both reward increasingly closer approximations of a desired behaviour, although this is perhaps a more salient aspect of the Lovaas than the SRP. An example of this in the SRP, is that the adult would respond quickly when crying was used to express a desire from a child who seldom expressed their needs in any way, but would not reward crying with a quick response when the child had developed sufficient language to express his or her desires in a more appropriate manner (The Option Institute & Fellowship, 1996).

It could also be argued that the two approaches are similar in that in both, the adult determines the child's activity to some extent: in Lovaas with the adult setting the tasks and in the SRP with the adult choosing which toys to put in the playroom (Aitken – personal communication). However, there is a large difference in the degree to which the adult determines the child's activity in the two interventions. In Lovaas the adult decides exactly what the child will do in each work session, whereas within Son-Rise the child can choose whatever activity they want. Whilst in Son-Rise the child is restricted to activities involving the toys which the adult has chosen to put in the playroom, the toys put in are usually ones which have the potential to be used for a wide variety of interactive games. In practice, therefore, the child has a high degree of control over what they will do.

As well as the obvious comparisons in terms of intensity and parental involvement, there are then common features in the techniques used in the two approaches. However, it seems that while some commonality does exist there are significant differences in the specifics of how these techniques are applied in the two approaches. In addition, although aspects of behavioural techniques do exist within the SRP, the two approaches differ at a fundamental

level in that the SRP is a child-led intervention whereas Lovaas is an adult-led approach. Allowing the child to take the lead and showing respect for the child's choices is arguably the most salient aspect of the SRP, pervading all of the techniques used within the programme. From this perspective, the SRP approach is very different indeed from the Lovaas approach (Jordan, 1990).

**4.8.2 Child-led and adult-led interventions**

Interventions for autism can be represented as a continuum from adult-led, directive interventions such as the Lovaas approach, to child-led approaches such as the SRP. Table 4.1 summarises the major differences between these two types of approach. Most obviously, within adult-led approaches the adult is largely responsible for setting the agenda, whereas within child-led approaches the child selects most of the tasks. This does not mean that the adult never selects tasks within child-led approaches, but it occurs less often and would never take precedence over a task which the child had selected. In adult-led approaches the focus is on the product of the interaction and the achievement of preset goals. In contrast, within child-led approaches, although the adult may have goals which they wish the child to achieve, this is secondary to the development of a mutually enjoyable interaction (Nind & Hewett, 1994). In addition, within child-led approaches if the child indicates that they do not wish to comply with the adult's request, the adult respects this wish, whereas within adult-led approaches there may be continued prompting for the child to follow through with the request. The approaches also differ in their treatment of 'socially inappropriate' behaviours, such as stereotypical movements and echolalia. Within adult-led approaches this behaviour would usually be ignored, or the child redirected to another activity. Within child-led approaches the adult would imitate this behaviour.

Table 4.1: Differences between adult-led and child-led interventions for autism

Adult-led	Child-led
Adult selects majority of tasks	Child selects majority of tasks
Focus on product of interaction	Focus on process of interaction
Prioritises achievement of preset goals	Does not prioritise achievement of preset goals
Some insistence that the child complies with requests	No insistence that the child complies with requests
Stereotypical behaviour discouraged	Stereotypical behaviour imitated

Sources: Kaufman, 1994; Knight, 1991; Knight & Watson, 1990; Lovaas, 1987; Nind & Hewett, 1994; Rogers *et al*, 1986; Sheinkopf & Siegel, 1998; Watson & Fisher, 1997.

There are also differences between the two approaches in the way they view language acquisition by children with autism. The adult-led style of interaction operates with the assumption that language is divisible into teachable parts. The child-led approach assumes that language is inextricable from a context of shared meaning and social use, and that children discover the properties of language through immersion in the communicative process (Norris & Hoffman, 1990).

Many of the child-led interventions also stem from a belief that the symptoms of autism can best be understood through Hobson’s affective-deficit theory (Hewett & Nind, 1998; Nind, 1997a & b; Wimpory, Chadwick, & Nash, 1995). This theory, described in Chapter 1, points to the need to address the core difficulties that children have in achieving shared understanding with others. As typically developing children begin to develop this understanding in the first year of life, child-led techniques therefore have much in common with patterns of early social interaction (Burford, 1993; Erba, 2000; Klinger & Dawson, 1992; Hewett & Nind, 1992; Sheppard, 1996). In such interactions the adult joins the infant’s own behaviour and repeats, comments upon, or expands it. There is responsivity to signals that the infant wishes to continue or terminate an interaction and preverbal communications are interpreted as being intentional. Although child-led interventions share many of these features of mother-infant interaction there is no assumption that the child is being ‘re-parented’, nor that the child is equivalent to an infant in all aspects of their development; appropriate respect must be shown for chronological age and experiences (Knight, 1991; Nind & Hewett, 1994).

There are many different child-led interventions (table 4.2). Although they differ in terms of intensity, therapeutic environment and level of parental involvement, all share the same core child-led principles described above.

Table 4.2: Types of child-led interventions

Intervention	Described by
Son-Rise Program (SRP)	Kaufman (1994)
Intensive Interaction	Nind & Hewett (1994)
Floor-time approach	Greenspan & Wieder (1999)
Music interaction therapy	Christie & Wimpory (1986)
The Playschool approach	Rogers <i>et al</i> (1986)
Strategies for facilitating social interaction	Klinger & Dawson (1992)
Non-directive therapy	Watson & Boucher (1996)
Movement therapy	Burford (1991)

It is clear that the SRP can best be understood within the context of child-led approaches. Despite the shared core principles, however, not all the child-led interventions are identical, and there are ways in which the SRP is unique. For example, within the SRP the child does not control when the intervention session ends, as is the case in Intensive Interaction. It also takes place in a 1:1 context, unlike Non-directive therapy which occurs in a group environment. There are in fact ways in which all the child-led interventions differ from each other somewhat. Perhaps though the most salient aspect of the SRP is the tremendous emphasis it places on the positive and accepting attitude of the adult working with the child and on the concern for how the adult's attitude to life in general can affect interactions with the child. While attitude is regarded as important in many interventions, including all of the child-led approaches listed above, nowhere is it described and emphasised so extensively as in the SRP.

#### **4.9 Research relating to the SRP**

As noted in Chapter 2, there is a distinct lack of empirical research into the effectiveness of the SRP. A number of anecdotal reports and case studies have described developmental gains in children involved in this approach, including improvements in eye contact, language and sociability (Hamilton-Ely, 1990; Jordan, 1990; Kaufman, 1981, 1994; Loumgair, 1997; Walters, 1994). However, such studies cannot conclusively show that progress is a direct result of the SRP as opposed to maturation, or simply due to an increase in 1:1 interaction with the child, irrespective of the techniques used (Howlin, 1997; Jordan, 1990; Loumgair, 1997). In many cases the long-term developmental gains for the child are also unknown (Howlin, 1997; Jordan, 1990).

While the majority of reported case studies are encouraging, not all found entirely positive outcomes. One case study into the use of the Program with a 3 year old girl with autism reported that, although gains were made in sociability and eye contact, development in language was less marked and that after a 3 year involvement in the program only limited overall progress was being made (Lynch, 1996, 1998). Howlin (1997) also notes anecdotal reports from teachers indicating that children returning to school following a full-time SRP have difficulty in re-adapting to school routine and display stereotypical behaviour that can be difficult to deal with.

In terms of effects on the family of involvement, there has again been little or no empirical research, although a number of authors have noted that it has helped families develop a more positive attitude towards their child's disabilities (Adams, 1993; Archer, 1997; Jordan, 1990;

MacDonald & Macdonald, 1991; Roberts, 1996; Walters, 1994). However, the demands which implementation of the program places on parents have also been noted (Gerlach, 1993; Jordan & Powell, 1993; Lynch, 1996, 1998).

While there has been no direct evaluation of the SRP, the use of Intensive Interaction, a very similar intervention, has been evaluated with six adults with severe disabilities, one of whom had autism. Increases in initiations of social contact, physical contact and time spent in interactive behaviours were found after the introduction of Intensive Interaction, with an absence of any other significant event which could account for the change (Nind, 1993; 1996). In Nind's study, Intensive Interaction was implemented in a way which was representative of how it is typically used, that is in a school rather than a home environment, by teachers rather than by parents, and with adults rather than with children – i.e. in different circumstances from how the SRP is typically used. Therefore, despite the similarities in technique between the two approaches, the inferences which might be drawn from this research regarding the potential effectiveness of the SRP for children with autism are extremely limited.

Although there is an absence of research on the SRP as a whole, there is related research which suggests that certain aspects of the approach might be beneficial, for some children at least. For example, Jordan and Powell (1993) note research indicating the benefits of using imitation, one of the main SRP techniques. Dawson and Adams (1984) and Tiegerman and Primavera (1984) found that the imitation of children with autism by an adult can lead to an increase in eye contact, smiling, touching and gesturing towards the adult. Dawson and Adams (1984) found that this was the case only with children who themselves had a low level of imitative ability, suggesting that not all children will benefit from this approach, although a later study found that the majority of children responded positively to this strategy, regardless of imitative level, IQ, or severity of autistic symptoms (Dawson & Galpert, 1990).

Imitation of typically developing infants by adults is common in the first year of life and may therefore be developmentally appropriate for some children with autism. Dawson and Galpert suggest that it may also be beneficial because it allows the child to lead the interaction, allowing the amount and type of simulation which is received to be regulated and ensuring that it is not too overwhelming. This in turn increases predictability for the child, a feature of interaction which Dawson and Lewy (1989) suggest is particularly beneficial for children with autism. Indeed, Ferrara and Hill (1980) found that the responsiveness of children with autism to their environment increased when the timing of events was

predictable. Imitation therefore seems to be an effective strategy, for at least some children, although it will probably be the case that if this technique is used exclusively for an extensive period the progress made by the child would plateau. Other strategies, such as expansion of the imitation, might need to be employed to ensure continuing development.

There are also research findings which suggest that the low stimulus environment of the SRP playroom may be beneficial. Hutt *et al* (1964) for example, report on an observation of 6 children with autism which found that stereotypical behaviour increased with increasing complexity of environment. However, it seems unlikely that minimal environmental stimuli will suit all children; each is likely to have an optimal level of stimuli (Zentall & Zentall, 1983), one which must be established by careful observation of patterns of response to the environment.

Some research suggests that when working with children with limited verbal abilities, a child-led approach, as described earlier in this chapter, may be more facilitative than an adult-led directive style. In a study of 5 preverbal children with complex disabilities, Norris and Hoffman (1990), for example, found that a child-led style of interaction led to a greater frequency and higher developmental level of communication. Increases in spontaneous social and communicative behaviour were also found by Peck (1985) when a child-led approach to teaching was introduced to 8 students with autism and/or learning difficulties who had limited use of language. Koegel, Dyer, and Bell (1987) similarly investigated whether a focus on child-preferred activities led to different levels of social avoidant behaviour (gaze aversion, moving away from the adult), in comparison to when activities were determined by the adult. In a study involving 10 children with autism and learning difficulties, they found that child-preferred activities were negatively correlated with social avoidant behaviour. Mirenda and Donnellan (1986) compared the effect of a child-led style of conversation to use of a more adult-led directive style. When adopted with 12 learning disabled adolescents, six of whom had autism, they found that the students initiated a significantly higher proportion of topics and produced a significantly higher number of spontaneous comments and questions in comparison to when their conversational partner used an adult-led style of conversation.

This correlation between the use of a child-led interactive style by the adult and communicative gains by the child has also been found in research with typically developing infants. Dunham, Dunham, and Curwin (1993) found that infants were more likely to learn the name of a novel object if it was labeled at times when it was the focus of the infant's

attention, rather than when the infant was focused on an alternative object. This was the case even when the frequency with which the infant looked at the object in the two conditions was the same. This supports findings from previous research (Tomasello & Farrar, 1986) and suggests that early lexical development is facilitated by a child-led style of interaction.

Studies into child-led interaction styles have tended to involve low intensity, short duration interventions which focused on immediate effects, rather than long-term gains. They do though indicate the facilitative effect of a child-led style in promoting communication, at least in children with limited use of verbal communication. However, it is not necessarily the case that this approach will be the most effective method for all children with autism, nor that it will be the most appropriate way for enhancing the development of all skills. For example, in a study of 12 children with a range of disabilities, DeGangi *et al* (1993) found that a structured adult-led approach was more helpful than a child-led approach for enhancing functional development such as self-help skills.

There are then certain aspects which make up the SRP which have been shown to be effective in promoting development in some children with autism, but nothing to indicate likely outcome when these techniques are used in combination, nor to suggest the likely long-term outcome of using such techniques. Only a longitudinal evaluation study could reliably provide such information, and to date no such study has been attempted.

#### **4.10 Overview**

The SRP combines the principles of acceptance and positivity from the Option Process with specific child-led techniques. While the program has a number of aspects in common with other interventions such as TEACCH and Lovaas, it is best understood within the context of child-led interventions, although its tremendous emphasis on the attitude of the adult sets it apart from many of the other child-led approaches and makes it unique. While individual techniques which make up the SRP have been evaluated to some extent, these cannot provide any indication of the effectiveness of the whole approach. Single-case studies have been undertaken which show developmental progress in children involved in this approach, but these cannot show conclusively that this progress was linked to SRP involvement. It is clear that an evaluation of this approach is much needed. However, this cannot be adequately carried out until a profile of the typical users and patterns of use of this intervention are established. This, as well as an exploration of the effects on the whole family of involvement in this approach, is addressed in Study 2, reported in the following chapter.

## CHAPTER 5

### STUDY 2. THE SON-RISE PROGRAM USERS' SURVEY

#### 5.1 Introduction

This chapter describes Study 2, a one-year longitudinal questionnaire study of families who had participated in a Start-Up course, the initial Son-Rise training described in the previous chapter. A number of the parents also participated in an interview study, designed to explore in greater depth a number of issues arising from Study 2. These interviews form Study 3 and will be reported in Chapter 6.

Studies 2 and 3 draw together two themes: family involvement in interventions for children with autism and the prerequisites for any evaluation of the efficacy of autism interventions. They aimed to:

- describe the experience of being involved in the SRP from the perspective of families implementing it, with a view to providing advice both for parents considering this approach and for professionals supporting those families;
- provide a profile of typical consumers of the SRP and of the range of ways in which it is implemented, with a view to aiding the design of any future evaluation of the efficacy of this specific intervention program.

The theme of family involvement in intervention has already been explored to some extent, in Chapter 2 with a review of the literature on the potential benefits and drawbacks for the family when parents take on the role of therapist, and in Chapter 3 with a study of parent intervention involvement within one Scottish region. Chapter 4 described the very high level of parent involvement required in the SRP, one which makes it likely that its implementation would affect the whole family, not just those directly involved in therapy sessions.

This chapter now develops a second interlinked theme: efficacy evaluation. Many of the interventions described in Chapter 2, including the SRP, have yet to be rigorously evaluated. Where evaluations have taken place, studies have often been unrepresentative of how the intervention is used outwith the research environment. For example, the characteristics of the



children participating in the evaluation have often differed from those with whom the intervention is typically used, in terms of age or diagnosis. Very often, the implementation itself may also have been unrepresentative; for example, the intervention has been used far more intensively in the research study than would normally be the case. This failure to ensure that evaluation design is typical of intervention use in the 'real world' greatly limits the generalisability of findings, a difficulty which could be avoided if a study profiling typical intervention users were first undertaken. Study 2 attempts to fill this gap in relation to users of the SRP.

There have been no evaluations to date of the SRP, but studies of the Lovaas method, another high parent involvement intervention (see p32), will be discussed in order to illustrate the kinds of evaluation problems which can arise.

Lovaas himself conducted a controlled evaluation of this method in 1987, with an experimental group of 19 children. It is likely, however, that this study was unrepresentative of the numerous families who subsequently used the Lovaas method, both in terms of the characteristics of the children involved and the pattern of implementation. The children, for example, were very young: the average age of the experimental group was 2 years 11 months at the outset of intervention. There are no figures on the typical age of children now involved in this intervention, but given that children with autism are often not diagnosed until five or six years of age (Howlin & Moore, 1997), it is very likely that children in the Lovaas study were younger than a typical sample would be. There have also been suggestions that the children involved in the Lovaas study were unrepresentative because of exclusions based on low mental age (Gresham & MacMillan, 1998; Schopler, Short, & Mesibov, 1989).

Lovaas' experimental group was also provided with 40 hours of intervention per week. Many families who actually use the method may not be able to provide such a high number of intervention hours, particularly those in rural areas who do not have access to a sufficient number of helpers (Anderson *et al*, 1987). Again, with no figures on typical use, it is impossible to say whether 40 hours per week is representative, but it does seem unlikely that most families could provide this level of intensity, particularly if the parents were also working. The fact that the study was administered from a university setting may also affect the generalisability of

results (Sheinkopf & Siegel, 1998). Parents did not, as would normally be the case, take responsibility for recruiting helpers, and both parents and helpers received extensive training. Normally when this intervention is implemented parents receive only three days initial training, with helpers being trained by the parents themselves (Birnbauer & Leach, 1993; Lovaas, 1996). While the Lovaas study reported an impressive level of intervention efficacy there are, then, a number of ways in which it may not have been representative of the families who subsequently used this method of intervention.

Subsequent evaluations of the Lovaas method have been designed to more closely reflect the way in which families are likely to implement the intervention, with fewer hours, older children, fewer helpers and less extensive training (Anderson *et al*, 1987; Birnbauer & Leach, 1993; Sheinkopf & Siegel, 1998). In general findings have been encouraging, but with no data on typical use it is still impossible to confirm the extent to which these more recent studies are representative. Some studies, such as that of Sheinkopf and Siegel (1998), drew samples from families who were already using the intervention prior to the study, and thus formed a more 'naturalistic' sample. However, there were only 11 children in the evaluation group, and the possibility remains that the sample was unrepresentative.

A very basic pre-requisite in designing any evaluation study is prior identification of the diagnostic and age profile of children typically involved in the intervention under evaluation. Family characteristics such as parental employment and whether there are siblings in the family should also be documented. These are rarely considered in autism intervention research although they may be useful predictors of outcome (Prizant & Rubin, 1999). Any study of consumers should also identify typical patterns in relation to duration of use, number of intervention hours per week, concurrent school attendance, concurrent use of additional therapies, number of volunteers, and the extent of parental and volunteer training. Only then can an evaluation study be designed to be representative of how the intervention is used outside the research environment, in the real world. Providing such a profile of Son-Rise users would undoubtedly be of benefit for the design process of any future evaluation.

There are of course difficulties in identifying 'typical' consumers of any intervention. Children with autism are an extremely heterogeneous population and for some interventions there may be

no clearly defining characteristics under which to group together the children involved. Undertaking a study profiling consumers would at least establish whether or not there is a 'typical' group of children with whom the intervention is commonly used. If the majority were a specific age and diagnosis, any subsequent evaluation could then be designed to be representative of these children. If the children involved were a less homogenous group, this would suggest that several parallel evaluation studies would need to be conducted. Identifying 'typical' patterns of intervention use may also be problematic, as there may be wide variation in the way in which different families implement the same intervention. It may, however, be possible to identify ways in which the majority of families implement the approach.

The study to be reported below, Study 2, focuses on the SRP from the perspectives of those families who use it. As noted in Chapter 2 there has recently been a shift towards a family-centred view which acknowledges that any intervention which involves the parents is likely to have an impact on the whole family. At least in some regions there has also been an increase over time in parental involvement in interventions, as reflected in the findings reported in Study 1. Yet there is still a conspicuous absence of research into both the effects of intervention involvement on family functioning and parental views on intervention efficacy (Jordan *et al*, 1998). This is quite remarkable given the numerous ways in which intervention involvement can impact on the family, including a reduction in the amount of time that can be spent with the other children in the family, increased parental stress, and financial hardship (Bristol, 1985; Koegel *et al*, 1982).

In Chapter 2 the literature describing the possible effects of intervention involvement on the family was reviewed. It revealed a complex picture with numerous factors likely to influence the extent to which the family is affected, including number of intervention hours per week, the child's progress, how confident parents feel about their ability to use the intervention, number and age of siblings, and so on. The influence of these variables can only be fully investigated if the sample size is large. This has rarely been the case to date. The majority of studies, moreover, have examined the effect on the family at a single time-point, either during the study or retrospectively (Holmes *et al*, 1982; Schopler *et al*, 1982). It seems reasonable to expect that effects on the family will vary over time. For example, stress may be higher at the beginning of

an intervention while the family adjust to the new situation. Ideally, therefore, research should be longitudinal (Jordan *et al*, 1998).

Parents' views on the efficacy of the intervention are also often undocumented, despite the potential richness of this source of data. Parents may notice changes which are not measured in standardised assessments because they relate more to 'real world' situations, such as whether the child can be taken shopping or to visit relatives. Changes which may be too subtle to be picked up by psychometric assessments may nevertheless be substantial in the parents' opinion and psychometric testing also takes no account of the fact that progress in some developmental areas may be valued by parents more than progress in other areas (Jordan *et al*, 1998; Runco & Schreibman, 1983). In addition, parents' opinions of effectiveness form over time, whereas standardised assessments measure effectiveness at a single time-point only and may not therefore give an accurate indication of progress, particularly if there is a lack of rapport with the tester (Atkeson & Forehand, 1978). The intervention which has been followed may also adversely affect test performance. If, for example, the child has been involved in an intervention which focuses on play and interaction, he or she may be at a disadvantage compared to children who have been involved in interventions focusing on table top work, the situation in which most IQ and language tests take place (Jordan *et al*, 1998).

This is not to suggest that standardised assessments are not an important part of measuring the effectiveness of an intervention. The need for objective psychometric testing is self-evident. All too often, however, this is carried out whilst 'social validation data' - the parents' own opinions on the effectiveness of the program - remain unreported (Armstrong *et al*, 1997; Holmes *et al*, 1982; Howlin & Rutter, 1987). Clearly it would be prudent to employ a variety of methods to present a cumulative body of outcome evidence for intervention effectiveness (Schopler *et al*, 1982).

A number of studies suggest that parents can accurately describe the behaviour and difficulties of their child with autism (Handleman, Harris, & Alessandri, 1990; Howlin & Rutter, 1987; Schopler & Reichler 1972). However, it may be the case that if the child has been involved in an intervention this will lead to a tendency for parents to rate their child's progress as being greater than other observers suggest, particularly if the parents themselves have been involved as

therapists (Atkeson & Forehand, 1978; Handleman, *et al*, 1990; Harel *et al*, 1977; Schopler *et al*, 1982). If parents have spent a great deal of money, time and energy involved in an intervention they may be reluctant to admit - even to themselves - that it has been ineffective.

Short (1984) notes that despite these caveats, gathering consumer opinion is a crucial part of any psychological intervention evaluation. Handleman *et al* (1990) also make the important point that differences in ratings of a child's progress across parents, professionals and psychometric testing does not necessarily mean that the parents' view is incorrect: they may interact with their child in a more relaxed atmosphere than professionals do and thus elicit optimal behaviour and communication. This suggests that the gathering of parental opinions on intervention efficacy is worthwhile, as long as findings are cautiously interpreted.

It is also important to look beyond the simple question of overall effectiveness towards identification of the particular areas of development parents feel the intervention is most and least effective in, and the factors which inhibit effectiveness. These may include child's diagnosis, age, number of intervention hours per week, parental confidence in ability to use specific techniques, uptake of ongoing parent training, and concurrent school attendance or involvement in other therapies (Howlin, 1997; Ozonoff & Cathcart, 1998).

The study to be reported below, Study 2, attempted to fill in some of these gaps. It represents the first large-scale study of the effects of involvement in the SRP by describing the families' experience from the time at which they first sought information on the approach through to training and implementation.

## **5.2 Research questions**

Study 2 was a longitudinal, questionnaire-based study. Over a one-year period it documented the experience of families using the SRP, profiling users and patterns of use, and soliciting parental views on the efficacy of the program for their particular child.

When gathering data on parental views of intervention effectiveness, there are two key methodological points that are relevant. Firstly, in order to avoid the possibility that parents feel unable to be critical, it is important that the information is collected by researchers who were not

involved in the training of parents (Bristol *et al*, 1996). Secondly, longitudinal data collection is advantageous as it allows examination of issues such as comparative effectiveness in earlier versus later months, and whether the various developmental areas show differential progress over the course of the intervention. Both of these requirements were met in the design of this study.

As noted, another limitation of many previous studies has been small sample size. By using a questionnaire approach the need for a large sample can be fulfilled at relatively low cost. Assuming it is properly representative, this can provide a 'true' and accurate profile of the children involved in the SRP and the patterns of implementation. It also allows statistical testing of the extent to which variables such as child's age and parental confidence influence family effects and program efficacy.

Three separate questionnaires (Appendix C) were sent over the course of a year to all families who had attended a one-week SRP Start-Up course in the UK in 1998. Questionnaire 1 was sent out immediately after the course, questionnaire 2 was sent out six months later, and questionnaire 3 was sent out at one year. Covering letters (Appendix C) emphasised that although the study was carried out with the full consent of the Option Institute, the researcher had no connection with the Son-Rise staff, and that parents should therefore feel free to express their views with confidence that these would be treated in the strictest confidence by the researcher. In all three questionnaires sent out it was made clear to parents that they were under no obligation to participate in the study, and that their personal details would remain confidential (see Appendix A for details of ethical considerations).

The study attempted to answer the following questions:

- (1) How do parents find out about the SRP?
- (2) Why do parents choose the SRP?
- (3) Why do parents who decide against implementing make this decision?
- (4) What are the characteristics of children involved in the SRP in terms of:
  - age?
  - diagnosis?

- (5) What are the characteristics of families involved in the SRP in terms of:
  - family composition?
  - parental employment?
- (6) How do families implement the SRP over the course of a year in terms of:
  - number of intervention hours per week (total hours)?
  - number of intervention hours provided by the parent (personal hours)?
  - concurrent school attendance?
  - concurrent use of additional therapies?
  - parental confidence in technique use?
  - parental confidence in running the program?
  - number of helpers?
  - hours of intervention provided by helpers?
  - ongoing training provided for helper therapists?
  - uptake of follow-up training and support by parents?
- (7) Effects on the family:
  - What are the effects on the rest of the family of intervention involvement, in particular in terms of stress, happiness, and finance?
  - Which variables influence effects on the family?
- (8) Effectiveness:
  - Overall how effective do parents feel the Program is for their child?
  - Are there any developmental areas for which parents feel the SRP is particularly helpful or unhelpful?
  - What factors influence program effectiveness?
- (9) Why and when do parents cease using their SRP?

### **5.3 Methodology**

The questionnaire study was carried out with the full consent of the Option Institute. A draft of the first questionnaire was sent to them for their approval and feedback, and based on extensive discussions with Option staff, some modifications were made before the questionnaire was piloted. To avoid any confusion, some of the definitions of Son-Rise techniques were changed so

that they were in line with the terminology used throughout the Son-Rise literature. A number of questions about volunteers were removed as the Option staff felt that it might undermine parents' confidence to ask them about this aspect at a stage when they may not even have begun to work with their child themselves. The cover letter was also amended to make it clear to parents that it was appreciated that they might find it difficult to fill in a questionnaire about their intentions so soon after the Start-Up course, given that they may not have fully planned how to implement their SRP. They were told not to feel concerned about this, again to avoid undermining their confidence. It was emphasised that parents should not feel obliged to carry out a Program precisely as they had described in the first questionnaire. This was to avoid parents suffering any feelings of guilt or inadequacy if they were not able to implement their Program as originally intended. The changes in terminology were intended to make parents clear about the precise aspect of the SRP they were being questioned about, thus increasing validity. The other revisions resulted in a more sensitive and ethically sound questionnaire.

In order to check the clarity of the questions, the first questionnaire was piloted on a family who had been using the SRP for some time. The mother felt that all questions were clear, but suggested that in the question "Does your child have any learning difficulties or physical problems" the phrase 'not yet established' should be added to the 'yes/no' options as many of the children involved in the SRP were likely to be young and still awaiting diagnosis.

### **5.3.1 Questionnaire One (Q1)**

Q1 was sent to all participants in the London Start-Up. 135 questionnaires were sent out on the basis of one per family/professional who had attended ( $n = 134$ ): an additional questionnaire was requested by a family with two children on the autistic spectrum. The focus of Study 2 was on the use of the Program with children on the autistic spectrum, but for reasons of client confidentiality the Option Institute could not divulge how many Start-Up participants were parents of children with autism, as opposed to professionals, volunteers, or parents of children with disabilities other than autism. For this reason Q1 was sent to all participants, who were then asked to specify whether they were a parent, a volunteer, or a professional, and to give information on the nature of their child's disability. The findings discussed in this chapter relate only to the questionnaires returned by parents of children with autism ( $n = 87$ ). Examination of Son-Rise use by other parents, volunteers and professionals was outwith the scope of this thesis.



At the time of the distribution of Q1 – immediately after the Start-Up course - most parents had not yet begun their SRP. Many of the questions therefore requested basic demographic details on the child's age, diagnosis, involvement in other therapies, and school attendance, as well as family details such as the number of siblings and whether the parents were employed. Information was also requested on the parents' intentions in relation to the use of the program at home, for example how many hours they hoped to do each week, how many volunteers they hoped to recruit, and how confident they were about using the various techniques.

### **5.3.2 Questionnaire Two (Q2)**

Q2 was sent out six months later, and requested information on whether the parents had gone on to set up an SRP for their child, and if so for how many hours it was used, whether the child continued to attend school and be involved in other therapies, and whether the running of the Program was affecting the rest of the family. There were also questions on the parents' experience of implementing the program and working with volunteers, and on whether they felt that their child had made progress or felt that there were areas where progress was less than they had anticipated.

Q2 was sent to the parents who indicated in Q1 that they intended to implement an SRP with their child ( $n = 77$ ). Parents who did not return Q2 after a reminder letter had been sent were then sent a shortened version, which contained questions on whether the parents had set up a program, how many hours the program was used for, and whether the child continued to attend school.

### **5.3.3 Questionnaire Three (Q3)**

This was sent out one year after the Start-Up course. At this stage a questionnaire was again sent out to all the participants of the Start-Up course, with the exception of the professionals and parents of children with disabilities other than autism, who had replied to Q1. Four types of questionnaire were sent out (Appendix C):

- **Q3A**

This was sent to parents who had been involved in an SRP at the time of Q2. This questionnaire covered many of the same questions as Q2 in order to investigate the families' changing experience. There were additional questions asking parents to rate how beneficial they felt the Program was for their child, and the extent to which it was affecting family stress and happiness.

- **Q3B**

This was sent to those parents who had indicated in Q2 that they had not yet begun an SRP but intended to do so in the future. This questionnaire investigated whether parents had gone on to set up an SRP. Those that had were then asked to complete Q3A. Those that had not were asked about the reasons for their decision, whether their interactions with their child had changed following the Start-Up course, and whether their child was involved in any other interventions.

- **Q3C**

This was sent to those parents who indicated in either Q1 or Q2 that they did not intend to begin an SRP. This questionnaire examined whether parents had continued not to use a Program and what the reasons were for their decision. It also examined whether the child was involved in any other interventions, parental perception of progress made by the child over the past year, any areas where progress was less than anticipated, and whether they felt that their interactions with their child had changed following the Start-Up course.

- **Q3D**

This was a short questionnaire sent to parents who had not replied either to Q1 or Q2, possibly because they had found these too time-consuming to complete. Q3D was only one page long and was largely 'tick box' in style, requesting information on whether the family had set up an SRP, and if so how many hours it was used for each week, and whether the child continued to attend school.

On each occasion, questionnaires were sent out with stamped return envelopes, to maximise return rate. Reminder letters were sent to non-returnees, approximately three weeks after the initial questionnaire had been sent. It was requested that the same parent filled in each of the three questionnaires over the year, as it was important that the results reflected the continuing experience of one member of each family.

### 5.4 Return Rates

Table 5.1 shows the return rate for each of the questionnaires. Of the 85 returns to Q1, three were from professionals, and a further three from parents of children with developmental disabilities other than autism; these people were not sent further questionnaires. 78 parents, representing 79 children on the autistic spectrum replied. Of these, all but two parents intended to begin an SRP with their child.

In Q2, 57 of the 61 replies were to the full version and 4 were to the shortened version. These came from:

- 47 parents (one of whom had 2 children on the autistic spectrum) who had begun an SRP (2 = short version replies).
- 6 parents who no longer intended to begin an SRP (2 = short version replies).
- 7 parents who had not yet begun an SRP but intended to do so in the future.

In Q3B one of the six returns was from a mother who had gone on to use an SRP; she therefore also completed Q3A.

Table 5.1: Return rates for questionnaires

Q'aire	Sent to	No. sent	No. returns	Return rate
Q1	All parents and professionals from Start-Up course	135	85	63%
Q2	Parents of cwa* who indicated in Q1 that they intended to use an SRP	77	61	79%
Q3A	Parents of cwa who indicated in Q2 that they were using an SRP	48	32	67%
Q3B	Parents of cwa who indicated in Q2 that they had not yet begun SRP but intended to in the future	7	6	86%
Q3C	Parents of cwa who indicated in Q1 or Q2 that they did not intend to begin an SRP	8	4	50%
Q3D	Those who had not replied either to Q1 or Q2	65	10	15%

\* children with autism

When the returns from all three stages of the questionnaire study are considered together, 94 of the 134 Start-Up participants returned at least one of the questionnaires, an overall return rate of 70%, well above average for a questionnaire-based study (Heberlein & Baumgartner, 1978). However, there is still the possibility that respondents differed from non-respondents (Borg & Gall, 1989; Cohen, Manion, & Morrison, 2000; May, 1993). For example, non-respondents may have been having more difficulties with implementation, or felt the Program to be ineffective. In theory this could have been investigated using follow-up interviews with non-respondents (Cohen *et al*, 2000). However, as the families had already been contacted on a number of occasions with reminder letters, it was felt that it would not be appropriate to contact them again, particularly when the stress of living with a child with autism may have been one of the reasons contributing to their lack of response.

Of the 94 replies, 87 came from parents/carers of children with autism (1 from a family with 2 affected children), 3 from professionals, 1 from a volunteer, and 3 from parents of children with disabilities other than autism. Only the findings from the 87 replies relating to children with autism will be discussed. Of these 62 were from mothers, 15 from fathers, and 2 from other relatives; a further 7 did not specify the family relationship.

## **5.5 Methodology for questionnaire analysis**

To allow an examination of how the parents' experience of the SRP changed over the course of the year it was necessary to study the same families at each time-point (0 months, 6 months, 1 year into the study). Not all parents using the SRP replied to every questionnaire. In total there were 25 families, representing 26 children, who returned all three questionnaires and were still running a program during the time of Q2 and Q3. Longitudinal analysis was therefore restricted to these 25 families. While the data from these 'longitudinal families' were very useful for analysing trends over the year the possibility that they were unrepresentative of the whole sample has to be acknowledged. They may, for example, have felt that the program was particularly beneficial or may have been more confident in their ability to use the techniques; there may also have been other, more subtle reasons for why they were still involved in both the SRP and the questionnaire study after one year. For this reason, the full data sets from each questionnaire, rather than just the longitudinal family data, were used for analysis whenever longitudinal issues were not being directly examined.

To try to gauge the extent to which the longitudinal parents were representative of all the parents who participated in the study some comparisons were made. Firstly, the longitudinal parents ( $n = 25$ ) were compared with those parents who had replied to Q1 and intended to use an SRP, but who had not replied to all three questionnaires and were therefore not 'longitudinal' ( $n = 51$ ) on a number of responses to Q1, including their confidence in using the techniques, their confidence in running a Program, the total number of hours they hoped to do each week, and the numbers of hours they personally hoped to work with their child for each week. The longitudinal families differed from the other families only in terms of the total number of hours of anticipated use; this was significantly higher for the longitudinal families ( $U = 352.0$ ,  $p < 0.05$ ,  $n = 76$ ).

At Q1 many of the questions related to families' intentions rather than actual program use, as many had not yet begun a program. The longitudinal families were therefore also compared to those parents who replied to Q2 and had implemented an SRP, but had not replied to all three questionnaires and were therefore not 'longitudinal' ( $n = 22$ ). Here longitudinal families did not differ significantly from other families on any of the variables mentioned above.<sup>1</sup>

Thus, as far as can be established, the longitudinal families were largely representative of the other families who participated in the questionnaire study and had implemented an SRP.

Note that where full data sets were used for certain analyses, with the exception of the analysis of demographic data, Q2 and Q3 data were used in preference to Q1. This is because Q1 related to parents' intentions, whereas Q2 and Q3 looked at what they had actually been able to achieve. Where either Q2 or Q3 could equally well be used Q2 was usually chosen as this was the larger of the two data sets, and thus more likely to produce representative results.

It is important to note that in the data analyses below, the number of parental responses occasionally varies across questions. This is because there were a few parents who did not answer all of the questions in questionnaires 1 - 3. The number of families providing data for each question is indicated as analyses are reported.

## 5.6 Questionnaire findings

### 5.6.1 How parents found out about the Son-Rise Program

In Q1 all parents (including the 2 who did not intend to use the Program) were asked how they first found out about Son-Rise ( $n = 78$ ). Figure 5.1 shows that a large proportion (56%) found out through television. In nearly every case this had been a QED documentary about Son-Rise, screened by the BBC in 1997, "I want my little boy back". Newspapers were the source of information for 15%. For half, this had been an article about a British family who had used the Program and felt that their child had improved greatly as a result. Very few parents found out through support groups or from professionals working with the child.

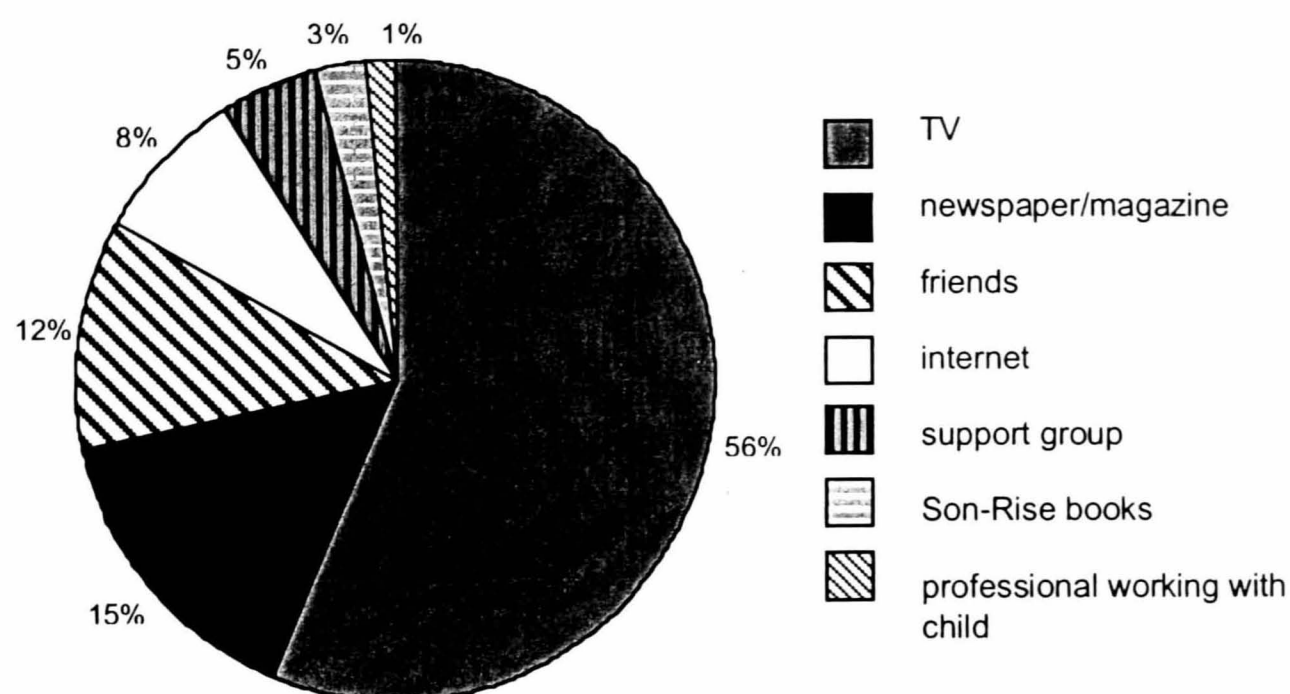


Figure 5.1: How parents found out about the Son-Rise Program (Q1)

### 5.6.2 Reasons for choosing the Son-Rise Program

In Q1 parents were asked which aspect(s) of the Program had attracted them to attend the Start-Up course. This was an open-ended question and many parents gave several reasons. These were coded into categories (table 5.2).

Table 5.2: Factors attracting parents to the Son-Rise Program (Q1)

What attracted you to this approach?	No. times reported
Attitudinal aspects of the approach	24
Techniques of the approach	17
Other aspects of the approach (e.g. "is manageable")	19
Believe it has shown positive results in the past	18
Suits family ethos/practical circumstances	16
Believe it will help child progress	15
Offers hope to parents	12
Offers empowerment to parents	8
Lack of viable alternative	8
Other	17

Aspects of the approach itself most often attracted families to Son-Rise. Most commonly this was due to the attitude it embodies, such as acceptance of the child and adopting a positive attitude to what she/he can achieve, rather than to its specific techniques. It is notable that 18 of the 78 parents believed that there had been positive results for other families who had used it. Given the paucity of rigorous evaluation studies the basis of this belief may be questionable.

### 5.6.3 Who chooses the Son-Rise Program?

Using data from all three questionnaires it was found that of the parents of the 88 children with autism who had replied to at least one questionnaire:

- 57 (65%) had begun an SRP with their child (including the family with two children on the autistic spectrum).
- 13 (15%) had not begun a Program and did not intend to in the future. Of these, 8 had intended to use a Program at the time of Q1 but had changed their minds at a later date.
- 18 (20%) planned to implement a Program in the future, but had not yet done so at the time of filling in the one or more questionnaires.

It should be noted that not all parents began their SRPs at the same time, although the majority began between Q1 and Q2.

**5.6.4 Reasons for not beginning a Son-Rise Program**

The 13 parents who chose not to begin an SRP were asked about their decision. All families gave several reasons (table 5.3). The most common was that they felt that Son-Rise was not suitable for their child.

Table 5.3: Reasons for not implementing the Son-Rise Program

Reason for not implementing Son-Rise	No. of times reported
Felt Son-Rise not suitable for child	10
Family circumstances	5
Using another intervention instead	3
Work commitments	2
Difficulties in setting up playroom	1
Financial reasons	1
Would conflict with methods used at school	1

One of the families who said that Son-Rise was unsuitable commented that they were keen to continue developing socialisation skills, and felt that using the Program would have meant that their child would have had fewer opportunities to develop these skills through peer interaction:

*“I’m not prepared to shut my child away to work with him as one of his main problems is socialising. He is six and it has taken this long to get him to accept being in situations with others. I don’t want him to go backwards.”*

Another parent commented on the practical difficulties of implementing the Program:

*“Son-Rise is a wonderful idea but a little idealistic and unrealistic. We all have lives to lead and don’t all have extended family and volunteers to help us. I agree with the principles but putting them into action is difficult without sufficient time, stamina and support.”*



Eight of the families nevertheless commented that they would continue to use some of the attitudes and/or techniques of the SRP:

*“Although we have decided not to pursue a Son-Rise Program, the course (Start-Up) I attended in London, however, has helped with my attitude, my feelings towards my son, and a lot of policies, ideas given on that course we use every day with our son, and I think we have changed and in turn so has our son. The future and present now appear better, we are far more content and optimistic.”*

### 5.6.5 Characteristics of children involved in the Son-Rise Program

Figure 5.2 shows the age distribution of children on entering the SRP. The average age was 5;8 years (SD = 2;6 years), and ranged from 2 years to 12;8 years. 40 (70%) of the children were male and 17 (30%) were female, a male:female ratio of 2.4:1.

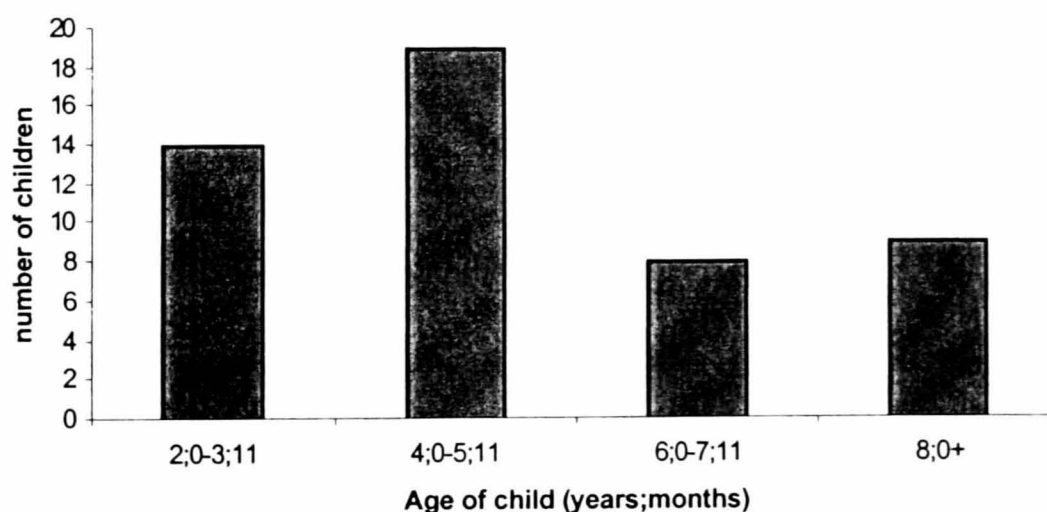
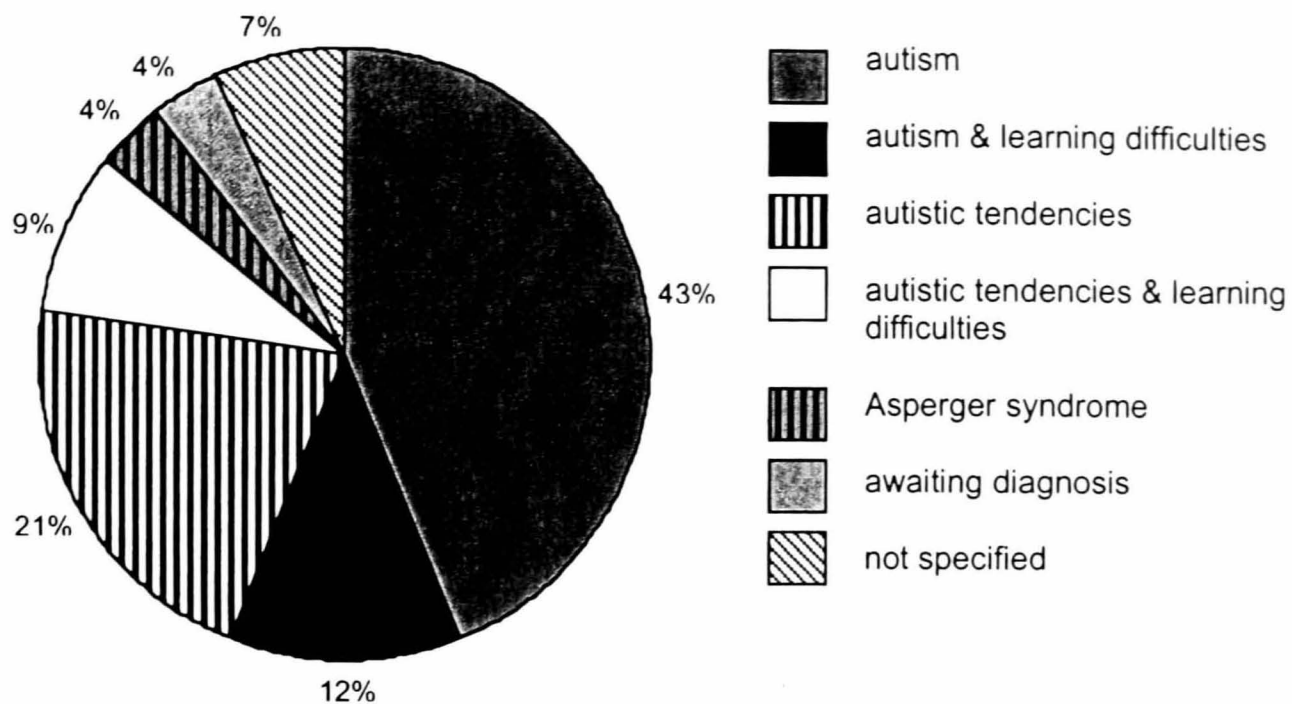


Figure 5.2: Age of children at outset of Son-Rise Program

As figure 5.3 shows the majority of children (55%) had a diagnosis of autism, 30% had autistic tendencies, and only 4% had Asperger syndrome. 21% had a diagnosis of learning difficulties in addition to their diagnosis on the autistic spectrum.



Notes:

- Children included in the category 'learning difficulties' included those whose parents indicated that their child had 'developmental delay' or 'global developmental delay'.
- Only children with confirmed learning difficulties were included in the category 'learning difficulties'; Learning difficulties in 5 of the 25 children with autism, 1 of the 12 children with autistic tendencies, and 1 of the 2 children with Asperger syndrome had not yet been confirmed.
- 2 children were awaiting diagnosis; in both cases the parents thought 'autistic tendencies' would be the likely diagnosis.

Figure 5.3: Diagnosis of children involved in the Son-Rise Program

On average parents began their Program 2;3 years after their child had been diagnosed; the maximum time after diagnosis that any parents began a Program was 6;8 years. Two parents began before a formal diagnosis had been given.

**5.6.6 Family characteristics**

In terms of family circumstances, 50 of the 56 families were two-parent families, 2 were single-parent families, and 4 did not specify. In 49 cases there were other children in the family, in 4 cases the child with autism was an only child, and in 4 cases it was not specified. Table 5.4 shows parental employment. In the majority of cases the father was in full-time employment and the mother was not employed.

Table 5.4: Employment of parents involved in the Son-Rise Program (Q1)

Mother’s employment	Father’s employment	No. of families
Not employed	Full-time	29
Part-time	Full-time	10
Full-time	Full-time	6
Not employed	Not employed	2
Full-time	Not employed	2
Other combination		3
Parents’ employment not specified		4

**5.6.7 Intensity of intervention implementation**

In Q1 parents were asked how many hours they would like the Program to be used with their child each week (total hours), and how many hours they personally would like to work with their child (personal hours). Q2 and Q3 examined whether parents had been able to fulfil their aims and if not, why they had been unable to do so.

To give an indication of the range of total and personal hours at any given time-point, the findings from Q2 are shown (figures 5.4 & 5.5; n = 46 and n = 41 respectively). Q2 findings are shown because Q1 examines intentions whereas Q2 shows what parents had actually been able to achieve.

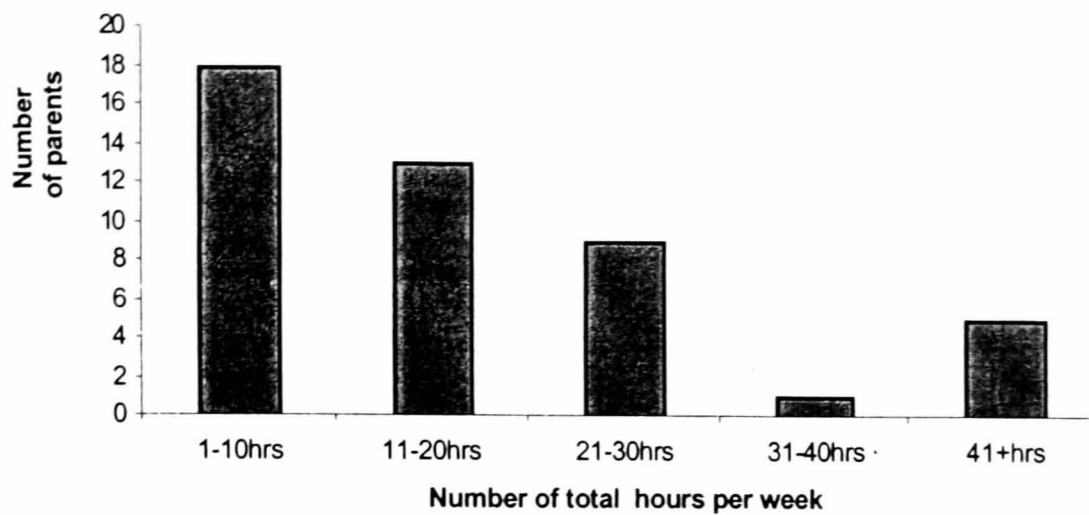


Figure 5.4: Total number of Son-Rise hours per week (Q2)

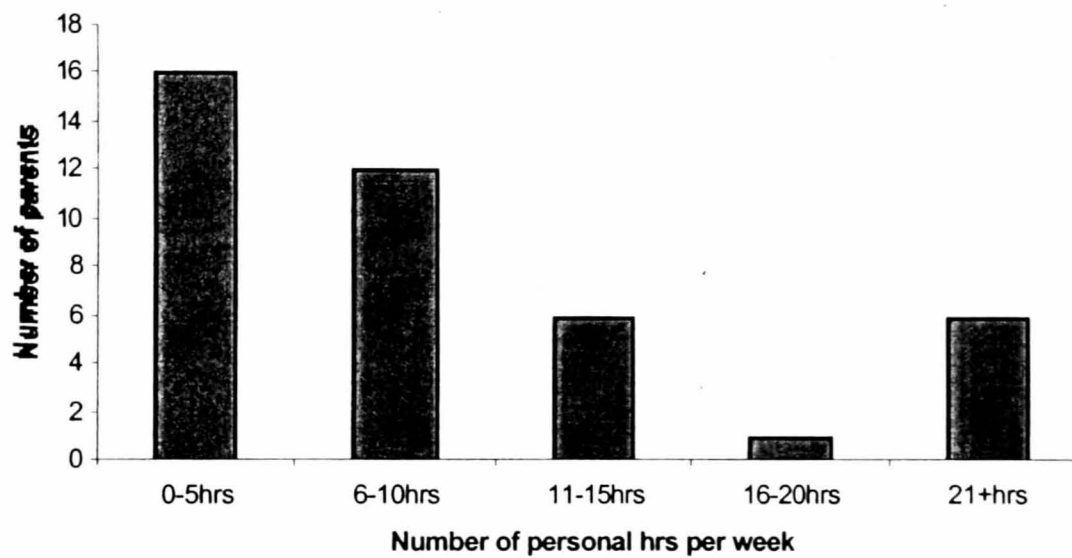


Figure 5.5: Number of personal Son-Rise hours per week (Q2)

To examine changes over time the data from the 25 longitudinal families were examined (table 5.5). By Q2 parents were using the Program for significantly fewer total hours than they had intended at the time of Q1 ( $t = 5.44$ ,  $df = 24$ ,  $p < 0.001$ ). There was no significant difference between Q2 and Q3. In terms of personal hours, parents were doing significantly fewer hours by Q2 than they had intended at the time of Q1 ( $t = 2.40$ ,  $df = 23$ ,  $p < 0.05$ ). Again, there was no significant difference between Q2 and Q3.

Table 5.5: Longitudinal families –number of total and personal Son-Rise hours per week (Q1-3)

questionnaire	min total hours	max total hours	average total hours	min personal hrs	max personal hrs	average personal hours
Q1	4	70	34	4	48	17
Q2	1	63	20	1	40	11
Q3	3	63	20	0	35	9

In Q3 parents were asked if they were happy with their total number of hours. The findings from the full Q3 data set of parents using the Program, rather than just the longitudinal families, will be reported. Of the 31 parents, 27 said they would like the Program to be used for a greater number of hours each week, 4 were happy with the number of hours, and 1 did not specify.

The parents who said they would like a greater number of hours were then asked why they were currently unable to do so. This was an open-ended question and parents often gave several reasons, with lack of volunteers being the major obstacle (table 5.6).

Table 5.6: Obstacles preventing increase in total hours (Q3)

Reason	No. of times reported
Lack of volunteers	20
Lack of energy	11
Work commitments	9
Family commitments	9
Other	7

In the data from Q2 (full data set), total hours was positively correlated with ratings of overall confidence in interacting using the techniques ( $r = 0.39$ ,  $p < 0.05$ ,  $n = 41$ ). There was no such correlation in the Q3 data.

In both Q2 and Q3 those who used the program for a greater number of total hours had also used the support services offered by the Option Institute on a greater number of occasions (Q2:  $r = 0.35$ ,  $p < 0.05$ ,  $n = 44$ ; Q3:  $r = 0.41$ ,  $p < 0.05$ ,  $n = 28$ ).

Number of personal hours was also related to effects on family life, and this will be described in greater depth in the 'Effects on family life' section (see p131).

### 5.6.8 School attendance

In Q2, parents were asked about their child's attendance at school during the course of their SRP. Of the 48 children involved in an SRP at the time of this questionnaire, 4 were not attending, nor had been prior to beginning the Program as the parents felt they were too young. Of the remaining 44 children, the majority continued to attend preschool/school on either a full or part-time basis (table 5.7).

Table 5.7: Children's school attendance (Q2)

School attendance	No. children (%)	School	Preschool
Continue to attend full-time	24 (55%)	18	6
Continue to attend part-time	11 (25%)	6	5
Discontinue	9 (20%)	6	3

To expand on these findings, parents were asked their reasons for continuing or discontinuing their child's attendance. This was an open-ended question and parents often gave several reasons. The most common reason given by parents was that they felt the school environment was beneficial for their child. Most often this was because of the enjoyment that school provided for the child. This was mentioned by 12 parents, while 10 mentioned the benefits of social interaction at school, and 4 felt that school was beneficial because of the skills their child learnt there.

Table 5.8: Reasons for continuing attendance at school or continuing on a part-time basis, as opposed to discontinuing completely (Q2)

Reason	No. times reported
Benefits of school	22
Two environments of school and Son-Rise compatible/beneficial/manageable	6
Child settled/can cope with school	5
Impossible to run a full-time Son-Rise Program	4
To avoid losing place at school	1
School supportive of Son-Rise Program	1
To allow time for self	1

Only four parents continued their child’s attendance because they felt it would be impossible to run a full-time SRP due to work commitments or a lack of volunteers. Three of these parents also mentioned that they felt that their child benefited from school. As table 5.8 shows, the majority chose to continue school attendance and run a part-time program because they felt that school was a good environment for their child, not because they were unable to run a full-time program and had no option but to send their child to school.

The parents of the 9 children whose attendance was discontinued as well as 2 of the 11 who continued part-time gave the reasons why they had reduced or suspended school attendance (table 5.9). The most common was that they were dissatisfied with their child’s school. In two cases this was because of the lack of 1:1 teaching, and in another two cases it was because their child was not encouraged to interact with other children.

Table 5.9: Reasons for discontinuing school attendance (or reducing hours at school) (Q2)

Reason	No. times reported
Dissatisfaction with school	7
Two environments potentially incompatible	3
Wish to run full-time Son-Rise Program	1
Because of progress made through Son-Rise Program	1
At teacher’s suggestion	1

There was no significant difference in age between children who continued to attend school and those that discontinued ( $t = -1.84$ ,  $df = 46$ , ns).

**5.6.9 Concurrent therapy use**

Q2 findings showed that 27 (56%) of the 48 children were involved in additional interventions during their SRP (table 5.10).

Table 5.10: Number of concurrent interventions (Q2)

No. of concurrent interventions	No. of children
0	19
1	15
2	6
3	3
4	1
5	0
6	2
not specified	2

The most common type of concurrent intervention was special diet, with a quarter of all children being given gluten and/or casein free food (table 5.11).

Table 5.11: Types of concurrent intervention (Q2)

Concurrent intervention	No. children involved
Diet (gluten and/or casein free)	12
Vitamins/minerals	8
TEACCH	6
Speech and language therapy	4
Music therapy	4
Homeopathy	4
Other	14

To establish the pattern of concurrent intervention use over time, the interventions used by the longitudinal families were examined. Of the 26 children in this sample, 22 were involved in another intervention at some stage of their Son-Rise involvement. Of these, 16 changed either the number or the type of concurrent interventions they were involved in between Q2 and Q3.



#### **5.6.10 Confidence in use of the Son-Rise techniques**

In each questionnaire parents were asked to rate how confident they felt in their overall ability to interact with their child using the Son-Rise techniques (from '1 = very confident' to '5 = not at all confident'). The data from the longitudinal families was used to examine changes over time. The mean confidence rating in Q1 was 1.9, i.e. very high. This dropped slightly to 2.2 at the time of Q2 ( $z = -0.95$ , ns,  $n = 24$ ), staying at this level at Q3.

Using the full data set from Q2, it was found that parents' confidence was positively correlated with total hours per week, as noted previously. Confidence was not significantly correlated with personal hours, although it approached significance ( $r = -0.31$ ,  $p = 0.051$ ,  $n = 39$ ). Confidence was not significantly related to program duration ( $r = -0.24$ , ns,  $n = 41$ ) nor to whether the child had autism or autistic tendencies, or had learning difficulties ( $U = 142.5$ , ns,  $n = 39$  and  $U = 126.0$ , ns,  $n = 41$  respectively).

In each questionnaire parents were also asked to rate how confident they were in their ability to use specific Son-Rise techniques over a one-hour session in the playroom. Overall, confidence in most of the techniques was fairly high, and again the data from the longitudinal families were used to examine changes over time (figure 5.6).

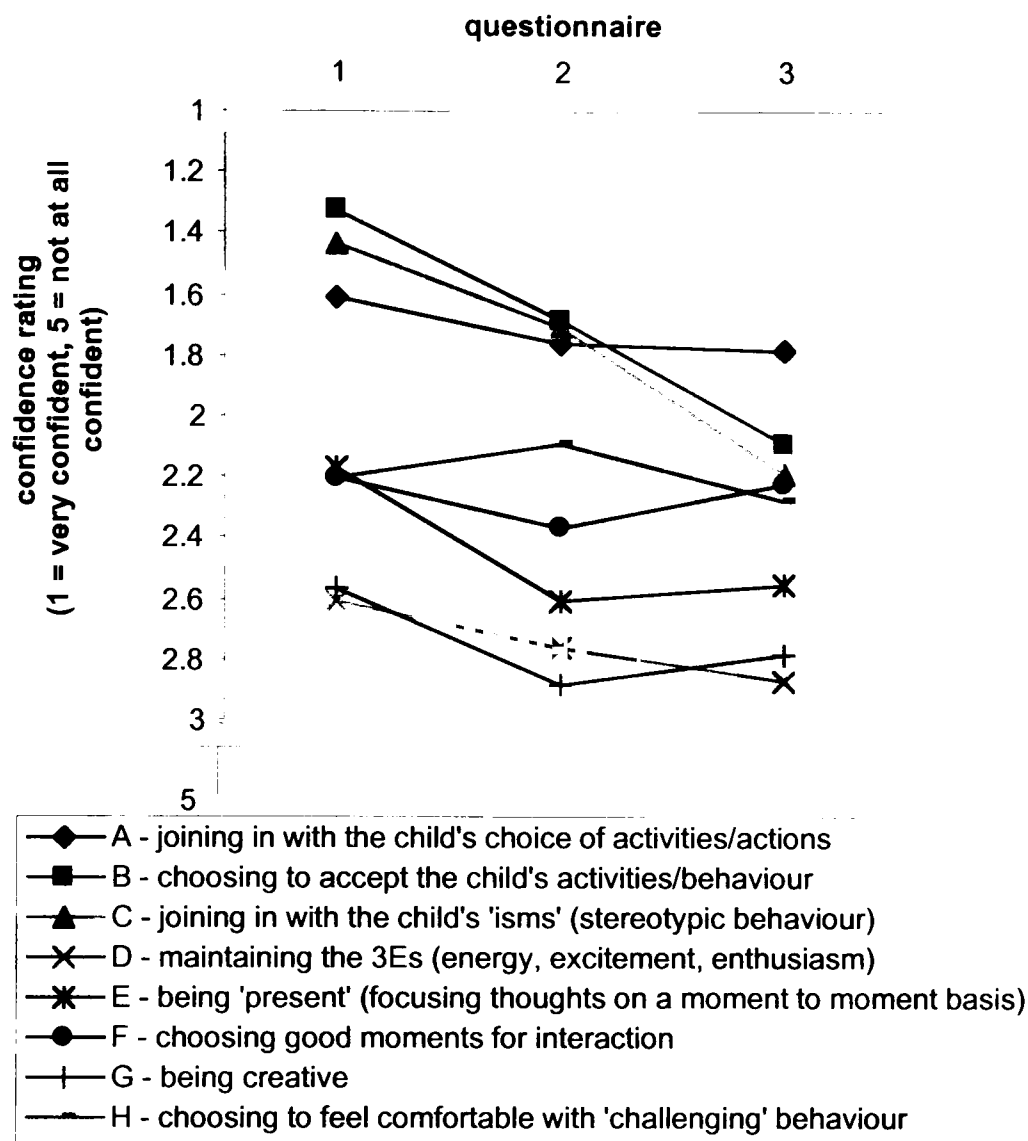


Figure 5.6: Parental confidence in the Son-Rise techniques (longitudinal families)

Confidence in all techniques remained stable over time, with the exception of the following significant decreases:

- Technique B – between Q1 and Q2 ( $z = -1.97$ ,  $p < 0.05$ ,  $n = 24$ ),  
– between Q2 and Q3 ( $z = -2.04$ ,  $p < 0.05$ ,  $n = 22$ ).
- Technique C – between Q2 and Q3 ( $z = -2.03$ ,  $p < 0.05$ ,  $n = 20$ ).
- Technique E – between Q1 and Q2 ( $z = -2.22$ ,  $p < 0.05$ ,  $n = 24$ ).

Some of these changes in confidence in technique use over time will be explored in greater detail later in this thesis, both in an interview study to be reported in the next chapter, and through a video analysis study of mother-child interactions over time, reported in Chapter 7.

5.6.11 Running a Son-Rise Program

In all three questionnaires parents were asked how confident they felt about running the program, i.e. recruiting and training volunteers, providing ongoing feedback, and holding meetings. They were asked to rate this on a five point scale (from ‘1 = very confident’ to ‘5 = not at all confident’). In the data from the longitudinal families the mean confidence rating in Q1 was 2.5, in Q2 it was 2.8 and in Q3 it was 2.9. This did not represent a significant change over time ( $\chi^2=1.26$ ,  $df = 2$ , ns).

Using the full data sets from each questionnaire, Wilcoxon tests on ratings at each time-point showed that parents were more confident about interacting with their child using the SRP than they were about running the Program (table 5.12).

Table 5.12: Mean confidence rating in interaction and running Son-Rise Program (Q1-Q3)

Questionnaire	n	Interacting with child	Running program
Q1	74	2.1	2.7***
Q2	30	2.2	2.8*
Q3	20	2.2	3.0**

\*  $p < 0.05$   
\*\*  $p < 0.01$   
\*\*\*  $p < 0.001$

In Q2 and Q3 parents were asked to rate specific aspects of running the Program from 1 = ‘very easy’ to 5 = ‘very difficult’. As the mean ratings from the longitudinal families in table 5.13 show, parents found recruiting sufficient volunteers and getting volunteers to work the desired number of hours the most difficult aspect. Although the ratings were somewhat lower at the time of Q3, this was not a significant decrease in either case.

Table 5.13: Mean parental ratings of difficulty of specific aspects of running Son-Rise Program (longitudinal families)

Aspect	Q 2	Q 3
Getting enough volunteers	3.75	3.89
Getting reliable volunteers	3.00	3.53
Getting volunteers who can work well	3.24	3.24
Getting volunteers to work desired number of hours	3.70	3.89
Training volunteers	2.95	3.17
Giving volunteers constructive feedback	2.95	3.00
Running useful meetings for your volunteer team	3.50	3.64

In Q1 parents were asked how many volunteer helpers they hoped to recruit. Q2 and Q3 examined whether parents were able to fulfil their aims (table 5.14). There was a significant difference between anticipated number of volunteers stated in Q1 and actual number of volunteers recruited by Q2, although not between the actual number recruited by Q2 and number recruited by Q3 ( $F = 4.19$ ,  $p < 0.05$ ,  $df = 2$ ; post-hoc Scheffe  $p = 0.05$ ).

Table 5.14: Number of volunteers (longitudinal families)

Questionnaire	Min	Max	Average (SD)
Q1	2	12	4.6 (2.19)
Q2	0	9	2.9 (2.62)
Q3	0	7	3.0 (2.37)

In Q1 parents were asked how many hours per week they would like each volunteer to work with their child. Q2 and Q3 examined how many hours volunteers actually worked (table 5.15). There was no significant difference between the number of volunteer hours hoped for in Q1, and the number reported in Q2 and Q3 ( $F = 1.131$ ,  $df=2$ , ns).

Table 5.15: Volunteer hours per week (longitudinal families)

Questionnaire	Min	Max	Average (SD)
Q1	1	10	4.6 (2.05)
Q2	1	9.7	3.3 (2.84)
Q3	1	12	3.8 (3.59)

In Q2, looking at the findings from the full data set, 14 of the 48 parents had no volunteers working with them. When asked an open-ended question about this, some gave several reasons (table 5.16).

Table 5.16: Reasons for not using volunteers (Q2)

Reason for no volunteers	No. times reported
Family could cover the hours	4
Wanted to gain confidence in own use of techniques first	3
Poor response to publicity	2
Lack of time to spend recruiting	2
Wary of having strangers in house	1
Other	3

In Q2 and Q3 parents were asked if they gave feedback to their volunteers on their use of the Son-Rise techniques. In Q2, of the 31 parents with volunteers, 24 parents provided feedback and 7 did not. The majority provided feedback on a weekly basis (15 of the 24). In Q3, 19 of the 22 parents with volunteers provided feedback, 1 did not and 2 did not specify. Again this was most often on a weekly basis.

In Q3 parents were asked whether they themselves received feedback from anyone, in addition to their use of Option Institute support services. Of the 31 families running a Program only 5 received feedback themselves; 18 families received no feedback while 8 did not specify. In 4 cases the feedback was provided by a partner and in 1 case from a volunteer on a weekly or fortnightly basis.

In Q2 and Q3 parents were asked if they ran meetings for their volunteers. In Q2, 17 of the 31 parents with volunteers held meetings, 12 did not, and 2 did not specify. In Q3, 11 of the 22 parents with volunteers held meetings, 10 did not, and 1 did not specify.

### 5.6.12 Evaluation of training courses

In Q2 the 48 parents were asked to rate on a 5-point scale how well they felt the Start-Up course had prepared them for running an SRP with their child, from 'very well' to 'not at all well' (figure 5.7). Four parents did not specify. Of the remaining 44, 'Sufficiently' was the most commonly stated response.

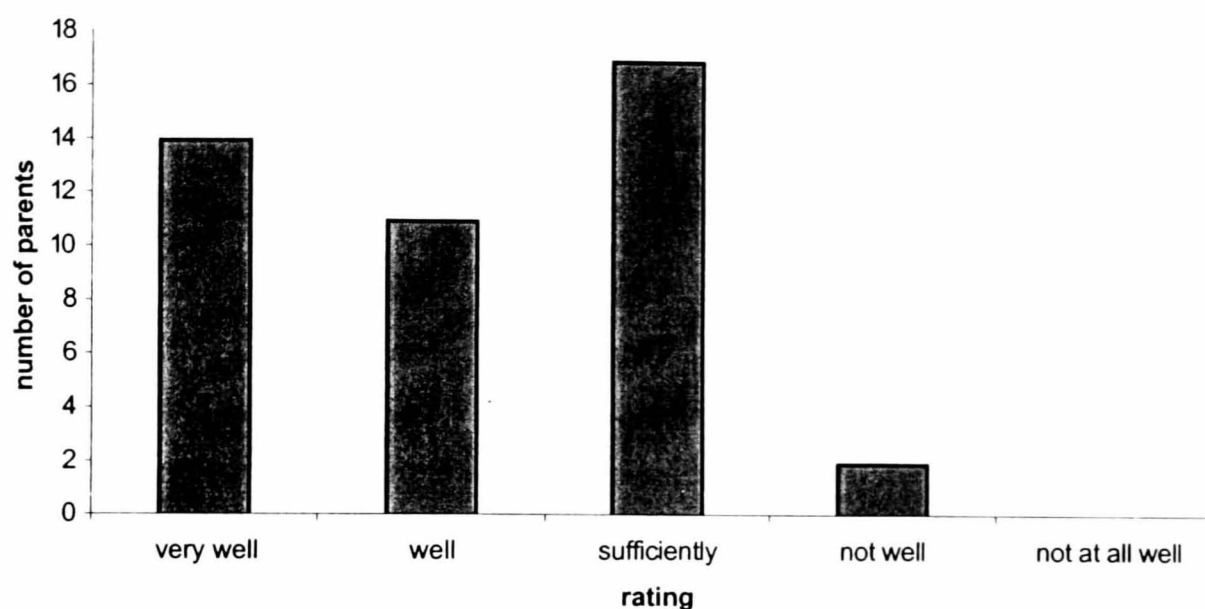


Figure 5.7: Parents' rating of how well the Start-Up course had prepared them (Q2)

In Q3 parents were asked if they had attended the Maximum Impact advanced training course which was held in London six months after the Start-Up course. 11 of the 31 parents had attended. Those who went on the Maximum Impact course were significantly more confident about their use of the Son-Rise techniques after the course than those who had not attended ( $U = 36.0$ ,  $p < 0.01$ ,  $n = 27$ ), although there had been no difference in confidence before the course ( $U = 40.0$ , ns,  $n = 27$ ). They were also significantly more confident about running the Program after the course than non-attendees ( $U = 27.0$ ,  $p < 0.05$ ,  $n = 22$ ). Due to small numbers, it was impossible to test whether there had been any significant difference in confidence in running the Program before the course.

In Q3 parents were asked to describe their experience of the Maximum Impact course. All 11 families who had attended were very positive about the course and said that it had increased their motivation and given them an energy and confidence boost:

*“My enthusiasm for Options had hit rock bottom but this course was just what I needed. I realised that I have all the answers/motivation needed to run the program. I came away feeling a totally new person with several layers peeled off. I also met some very good friends and since we shared such a lot will stay good friends for a long time.”*

**5.6.13 Uptake of support services**

In Q2 and Q3 parents were asked how often they had made use of the follow-up support services provided by the Option Institute (see Chapter 4 for a description of these services). In Q2, 20 of the 47 parents who were running an SRP (43%) had used the support services (table 5.17).

Table 5.17: Support service uptake (Q2)

How many times support services used	No. parents (%)
Never	25 (53%)
Once	6 (13%)
Twice	7 (15%)
Three times	4 (9%)
More than three times	3 (6%)
Not specified	2 (4%)

Families who did use the support services used them on average once every 3 months. Phonecalls to the Option Institute was the most common service, with 20 families making use of this service. Only two families had used video-feedback and only one had had a trained Son-Rise teacher visit them in their home.

The 25 parents who had not used the support services were asked about their reasons for this. Thirteen said they hadn’t felt the need, either because their Program was still at an early stage, or because they felt the Start-Up course and Son-Rise literature had prepared them adequately. Seven had been put off by the cost. Two parents said they had not found the time and a further two said they lacked the confidence to talk about their efforts as their child’s therapist.

Q3 findings showed that 18 of the 30 families had never used the support services and 12 had. Use was related to perceived efficacy (see ‘Parental perception of efficacy’ – p135). Also, those who used the services were using Son-Rise for a significantly greater number of hours each week than those who had not used them ( $U = 48.5, p < 0.05, n = 28$ ). This was not the case in Q2, although it did approach significance ( $U = 149.0, p = 0.053, n = 43$ ).

### 5.6.14 Effects on family life

#### *Benefits and drawbacks for the family of being involved in Son-Rise*

In both Q2 and Q3 parents were asked whether involvement in the SRP affected family life. This was an open-ended question and many parents noted a number of both benefits and drawbacks. 16 (34%) of the 47 families in Q2 noted benefits and 25 (53%) noted drawbacks. Figures were similar in Q3. At this stage 12 (39%) of the 31 families noted benefits and 18 (58%) noted drawbacks.

Table 5.18 shows the types of benefits noted by families in Q2. The most commonly noted benefit was that the family felt more positive emotionally. The types of benefits noted at this stage were very similar to the types noted in Q3.

Table 5.18: Benefits for the family of being involved in Son-Rise (Q2)

Benefit	No. of times reported
Family feels more positive	6
Helps interactions between family members	5
Family more accepting/understanding of child with autism	4
More attention/better quality time for other children	1
Volunteers beneficial for other children	1
Other	2

There were no significant relationships between hours of intervention and family benefits in either Q2 or Q3, with the exception that parents noting benefits in Q2 did significantly fewer personal hours than those who did not note a benefit ( $U = 103, P < 0.05, n = 38$ ). Duration of Program did not influence whether benefits were noted in either Q2 or Q3 (Q2:  $U = 172.5, ns, n = 39$ ; Q3:  $U = 60.0, ns, n = 26$ ).



Table 5.19 shows the types of drawbacks noted by 25 of the families in Q2. Again these were very similar to the content of comments made in Q3. Nearly half the families noted that Son-Rise involvement meant that they had less time to spend with their spouse and other children.

Table 5.19: Drawbacks for the family of being involved in Son-Rise (Q2)

Drawback	No. of times reported
Less time to spend with spouse/other children	20
Other children feel left out	5
Divides the family	2
Other	4

Three of the families noting drawbacks commented that these were minimal. A further four said they tried to minimise the negative effects, e.g. by using the Program when the other children were at school. Three families felt that their awareness of negative effects had caused them to reduce the amount of time they spent using the Program. Three families commented that having more volunteers would reduce negative effects.

Parents who noted 'less time to spend with spouse/other children' in Q2 used the Program for a significantly greater number of total hours than parents who did not note this drawback ( $U = 124.5$ ,  $p < 0.05$ ,  $n = 40$ ), although this was not the case in Q3 ( $U = 73.5$ , ns,  $n = 27$ ). Duration of Program did not influence whether drawbacks were noted at either the Q2 or Q3 stage (Q2:  $U = 154.0$ , ns,  $n = 39$ ; Q3:  $U = 76.5$ , ns,  $n = 26$ ).

Parents who noted drawbacks in Q3 were those where the child with autism had significantly more siblings under the age of 11 years ( $U = 68.0$ ,  $p < 0.05$ ,  $n = 30$ ).

### ***Does the Son-Rise Program make family life more stressful?***

In Q3 the 31 parents using the Program were asked to rate, on a five-point Likert scale, the extent to which involvement in it had affected family stress. There was a fairly equal spread of parents who felt that it had made family life more stressful and of those who felt it had made it less stressful (figure 5.8).

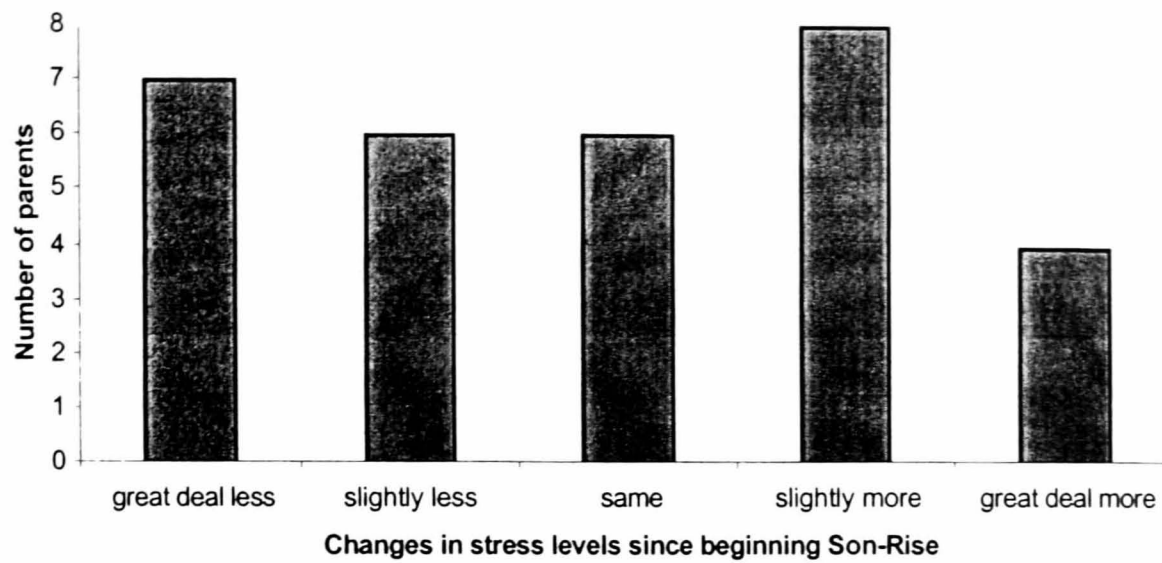


Figure 5.8: Stressfulness of family life since beginning the Son-Rise Program (Q3)

Stress was not significantly correlated with personal hours, total hours or duration of intervention ( $r = 0.12$ , ns,  $n = 31$ ;  $r = 0.07$ , ns,  $n = 31$ ;  $r = 0.31$ , ns,  $n = 28$  respectively)

***Does the Son-Rise Program make family life happier?***

In Q3 parents using the program were also asked to rate on a 5-point Likert scale the extent to which involvement in it had affected family happiness (figure 5.9). The majority of respondents found that family life had become happier since beginning an SRP.

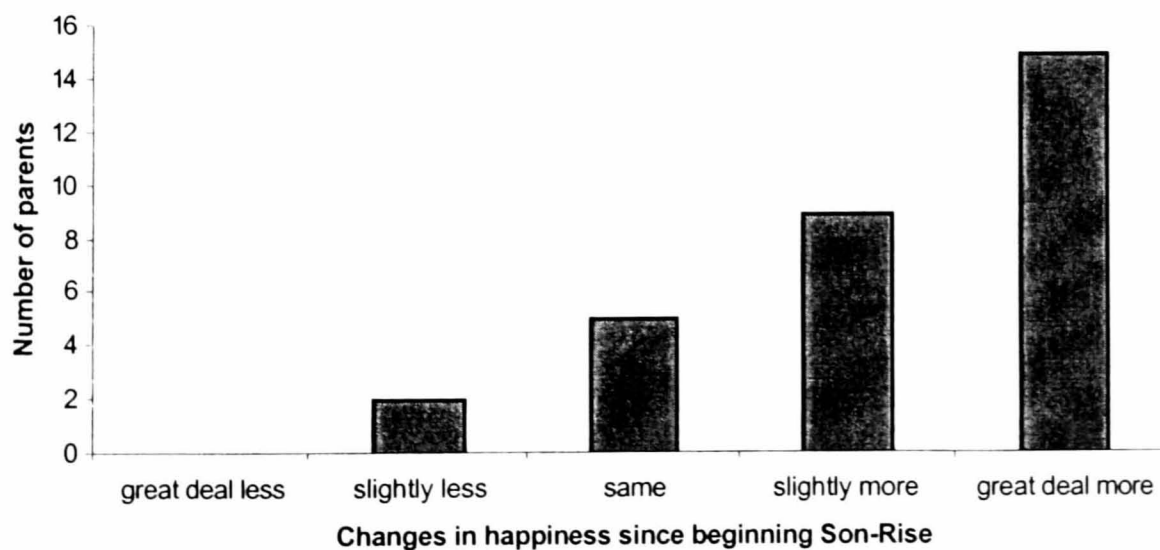


Figure 5.9: Happiness of family life since beginning the Son-Rise Program (Q3)

Happiness was related to experiencing less severe intervention-related financial difficulties ( $r = -0.39$ ,  $p < 0.05$ ,  $n = 30$  – see below), but not to Program duration ( $r = -0.13$ , ns,  $n = 28$ ). It was related to holding meetings for volunteer helpers ( $U = 56.0$ ,  $p < 0.05$ ,  $n = 29$ ).

#### 5.6.15 Financial effects of running a Son-Rise Program

Families most commonly experienced only slight financial difficulties as a result of their involvement in Son-Rise, but these were severe in 5 cases (figure 5.10). Only 4 of the 31 parents who responded to this question noted no financial effects in relation to their use of the Program.

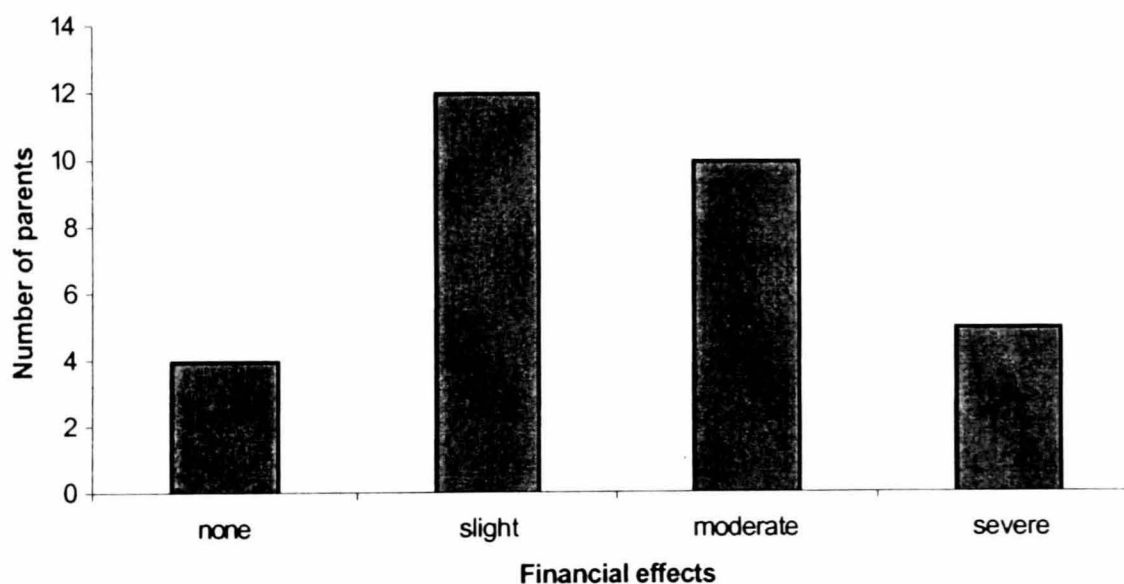


Figure 5.10: Financial effects of Son-Rise Program involvement (Q3)

Financial difficulties were not associated with drawbacks for the family ( $U = 66.5$ , ns,  $n = 29$ ), or with increased family stress ( $r = 0.12$ , ns,  $n = 30$ ). As noted, however, it was connected with a lack of increased family happiness.

Of the 31 families using the Program at the Q3 stage, 17 had not undertaken any form of fundraising, 5 had had funds raised for them by others, and in 9 the immediate family only had been involved. Family fundraising was not associated with increased family stress ( $U = 85.0$ , ns,  $n = 31$ ).

#### 5.6.16 Parental perception of efficacy

In Q3 parents were asked to rate on a four-point Likert scale how beneficial they felt the SRP was for the child (table 5.20). 'Very beneficial' was the most commonly stated response.

Table 5.20: Parents' rating of how beneficial the Program had been for child (Q3)

Rating of how beneficial Program had been	No. of children
Not at all	0
Slightly	7
Moderately	8
Very	16
Not specified	1

This efficacy rating was not significantly correlated with the child's age, nor with total hours or program duration ( $r = -0.08$ , ns,  $n = 31$ ;  $r = 0.32$ , ns,  $n = 30$ ;  $r = 0.11$ , ns,  $n = 27$ , respectively). There was a significant correlation between perceived efficacy and the number of times parents had used the Son-Rise support services ( $r = 0.44$ ,  $p < 0.05$ ,  $n = 28$ ).

There was no correlation between perceived efficacy in Q3 and confidence in technique use as reported in either Q2 or Q3 ( $r = 0.35$ , ns,  $n = 26$ ;  $r = 0.25$ , ns,  $n = 27$  respectively). However there was a significant positive correlation between perceived efficacy in Q3 and confidence reported in Q1 ( $r = 0.43$ ,  $p < 0.05$ ,  $n = 30$ ).

Perceived efficacy was related to family effects. In Q3 families noting benefits of intervention involvement on family life thought that the Program was more beneficial for their child than did parents not noting benefits on family life ( $U = 58.5$ ,  $p < 0.05$ ,  $n = 29$ ). Perception of efficacy was positively correlated with family happiness and negatively correlated with family stress ( $r = 0.70$ ,  $p = 0.001$ ,  $n = 31$  and  $r = -0.47$ ,  $p < 0.01$ ,  $n = 31$  respectively).

There appeared to be no relationship between diagnostic category (autism, autistic tendencies, Asperger syndrome) and perceived efficacy, although the numbers in any one group were too small to test this statistically. However, there did seem to be a connection between efficacy rating and presence of learning difficulties. Only 1 of the 16 children in the ‘very beneficial’ group and 1 of the 8 in the ‘moderately beneficial’ group had confirmed learning difficulties, whereas 4 of the 7 children in the ‘slightly beneficial’ group did. Again, the numbers in each group were too small to test this statistically.

The 15 parents who rated their child’s progress as ‘slight’ or ‘moderate’ were asked which factors they felt had limited the efficacy of their SRP. This was a tick box question, and parents often indicated more than one factor (table 5.21).

Table 5.21: Factors limiting efficacy of Program (Q3)

Reason	No. times reported
Number of hours the Program is used for each week	14
Parents’ ability to use the Program	11
Family circumstances	10
Suitability of the Program for the age of child	3
Suitability of the Program for diagnosis of child	1
Other	2

In Q3 parents were asked to select the description which best matched their child’s progress (table 5.22). Response varied across parents, with ‘minor but constant’ being the most common.

Table 5.22: Child’s pattern of progress (Q3)

Pattern	No. of children
Little or no progress	0
Minor but constant progress	9
Intermittent spurts of minor progress	7
Intermittent spurts of substantial progress	6
Initially substantial followed by minor progress	2
Initially minor followed by substantial progress	1
Constant substantial progress	4
Other	3

In Q2 and Q3 parents were asked to describe in which developmental areas, if any, their child had made progress. This was an open-ended question and parents often indicated several areas. As table 5.23 shows, the main areas of progress reported in both Q2 and Q3 were eye contact and social interaction, followed by language.

Table 5.23: Areas of child's progress (Q2 & Q3)

Area of development	Q2 (n = 48 children)	Q3 (n = 32 children)
Eye contact	36	23
Language	34	20
Social interaction	30	24
Attention span	17	10
Stereotypical behaviour/repetitive routines	16	8
Academic skills	16	8
Play skills (imaginary play, toy play)	13	13
Challenging behaviour	13	8
Self-help skills (toilet training, eating)	11	9
Awareness of surroundings	6	5
Other	8	4
Not specified	4	0

In Q2 and Q3 parents were asked about developmental areas in which progress had been less than they would have hoped (table 5.24). Again, this was an open-ended question and some parents noted more than one area. Language was the area most often picked out, mentioned by parents of half of the children. It is worth noting that for 8 of these 16 children, parents had nevertheless noted some progress in language.

Table 5.24: Areas of development where progress had been less than hoped (Q2 & Q3)

Area of development	No. children Q2 (total n = 48 children)	No. children Q3 (total n = 32 children)
Language	13	16
Self-help skills	4	4
challenging behaviour	4	3
Social interaction	3	5
Stereotypical behaviour/repetitive routines	3	2
Play skills	3	0
Attention span	3	0
Other	6	3
Most areas	2	1
No areas	7	5
Too early to say	6	0
Not specified/don't know	9	1

In Q3 parents were asked why they thought there had been less progress than they had hoped for in the particular developmental area they had noted. 25 parents completed this open-ended question, often stating more than one reason (table 5.25). The most commonly given reason was that it was due to the way in which the Son-Rise techniques had been applied. Some of these parents felt that they had challenged their children too little, while others felt that they had challenged them too much.

Table 5.25: Reasons why development was less than anticipated (Q3)

Reason	No. of times reported
Due to way in which Son-Rise techniques applied	11
Lack of time in playroom	4
Severity of child's symptoms	3
Age of child	1
Other	5
Don't know	7

### 5.6.17 Reasons for ending use of Son-Rise Program

6 of the 57 parents who began a Program stopped using it within the first seven months. Work commitments, illness, difficulties recruiting volunteers and changing to another intervention were all provided as reasons. Two of the parents hoped to be able to return to using the Program in the future. A further two had stopped using Son-Rise to begin using an ABA Lovaas-type approach. Both commented that they liked the philosophy of Son-Rise but had been put off by the glossy literature containing “emotional anecdotes” by parents. One felt that because her child was non-verbal there were few developmental areas that could be built on easily, and that the lack of structure made the Program difficult to implement, as did the lack of local support. Both felt that their children had made a great deal more progress through Lovaas, in one case particularly in the area of language. When asked whether Son-Rise had been a good foundation for Lovaas one parent said that she wished she had used Lovaas all along rather than Son-Rise. The other mother was not sure:

*“Sometimes I do wonder that perhaps my son was only ‘ready’ for an ABA intervention as a result of the trust and comfort he gained from engaging in the Son-Rise approach for seven months. However I also wonder if perhaps he might indeed be further along the road if he had begun an ABA home programme in July of '98 rather than the Son-Rise Program.*

Not all the parents ceased using the Program because of dissatisfaction or difficulties with implementation. One parent commented:

*“My child has made such good progress I feel it is now more beneficial for him to spend time with siblings and friends, instead of in a playroom with adults.”*



## 5.7 Discussion

The aim of this questionnaire study was to provide a profile of the children involved in the SRP and the patterns of its implementation. The findings showed a heterogeneous group of children involved and a wide range of ways in which the program was implemented by parents to suit their own child and family circumstances.

Children ranged in age from 2 to 12 at the outset of intervention, with average age being 5;8 years. The most common diagnosis was autism with no additional learning difficulties. It would be advantageous therefore to prioritise this age range and this diagnostic grouping in the design of any future evaluation study. Such a prioritisation is not to deny that the Program is being used with other children, and in the longer-term evaluation studies should also involve older children and children with a diagnosis elsewhere on the autistic spectrum.

In terms of family characteristics, there were very few single parents families involved, although it is uncertain whether this was for financial reasons or due to the logistics of running a Program without the support of a spouse. In the majority of families the mother was not employed and the father was in full-time employment, although there were a handful of families where both parents were in full-time employment. The interview study, which was designed to link in with this questionnaire study and is to be reported in the next chapter, looks more closely at how mothers who were employed found the experience of combining work with running a Program.

When patterns of implementation were examined the most notable finding was that although there were families who used the Program exclusively and intensively, the picture on the whole was of less intensive use combined with school attendance and involvement in other interventions. By Q2 the longitudinal families were using the Program for an average of 20 hours per week, with parents personally working with their child for an average of 11 hours. This represents an enormous time commitment by the parents, but is very different from the popular image of Son-Rise parents who “lock themselves in a bathroom and imitate their child’s every movement for 72 hours” (Siegel, 1996). Both total and personal hours were significantly less than parents had originally intended, and parents considering using the Program should be prepared for the fact that they may not be able to use the Program as intensively as hoped. However, this does not necessarily mean that there will be no progress. Studies into other

interventions, such as the Lovaas method, have found that 20 intervention hours per week can bring about substantial improvement in some children (Anderson *et al* 1987; Birnbrauer & Leach, 1993), and indeed the parents involved in the third questionnaire of this study all felt that the SRP had been of some benefit to their child's developmental progress.

Surprisingly, it was found that the majority of children continued to attend school. Parents, on the whole, regarded school as a beneficial environment for their child and continued their child's attendance for positive reasons - because they chose to, not because they were unable to run a full-time program and had no alternative but to send their child to school. The interview data in the next chapter explore further how school and Son-Rise can work well together and how parents feel that the child copes with any conflict in interactive style between the two environments.

The majority of children were also involved in other interventions. This may cause problems in any evaluation study, as it would make it difficult to attribute change solely to the SRP (Jordan *et al*, 1998; Prizant & Rubin, 1999). The data from the longitudinal families highlighted this difficulty, indicating the numerous changes in the type and number of other interventions that the children were involved in even in this relatively short period of time, of one year. Possible solutions include asking parents involved in any evaluation not to use any other interventions, although the ethics of denying parents this opportunity are questionable, particularly if they then find the SRP to be ineffective with their child.

Previous evaluation studies of interventions such as the Lovaas method were criticised as being unrepresentative because of the large number of highly trained helper therapists provided for the families (Anderson *et al*, 1987). The study reported here found that parents had an average of 3 volunteers who each worked an average of 3-4 hours per week, the majority of parents providing weekly feedback training for their volunteers. Lack of volunteers was a major difficulty, however, with parents citing this as the main obstacle preventing them from increasing the number of intervention hours that their child received. Parents considering using the approach should therefore bear in mind that number of volunteers might be the factor that ultimately dictates the intensity of program that they will be able to provide. A potential solution would be

for universities to provide course credits for volunteer work, although this would not help families in rural areas, who presumably have the most difficulty finding volunteers.

There was wide variation in families' implementation of the SRP. It is important that the Program is taught in such a way that parents do feel able to adapt it to their own circumstances, rather than feeling inadequate if they cannot live up to some 'gold standard' of intervention delivery which may be neither appropriate nor practical for them. Despite this variation, a profile of the typical children and typical patterns of use of the Program was still identifiable. Again, it would be advantageous to design any subsequent evaluation of the efficacy of the SRP around these profiles.

This study also examined the experience of families involved in the SRP, from first finding out about it, through to implementation. It was notable how many parents found out about this approach through the media, and how few through professionals or support services. This is in line with previous research showing that at the time of diagnosis professional advice on home-based interventions is extremely limited in the UK (Howlin & Moore, 1997). The exceptionally high proportion finding out about the Program through the media may be a feature of this particular sample, however, as the BBC had recently aired a documentary on Son-Rise. Given the power of such television broadcasts in determining which interventions parents will use, the media must act responsibly, emphasising that some parents may have difficulty in implementing the approach or find it to be ineffective, rather than focusing exclusively on 'success stories'.

It is concerning that parents chose this approach because they believed it had been effective for other families. Reading of or witnessing positive outcomes in another family can be very motivating, and it certainly makes more sense to embark upon an approach which one believes has worked for other families, as opposed to one for which no evidence at all of effectiveness exists. However, apart from anecdotal reports, there has been no direct empirical evidence of significant measurable progress using this method and, while parents may see progress in the children of other families, it may well be the case that what works for one child will have no effect or even be detrimental for others (Bristol *et al*, 1996; Howlin 1998a; Simpson, 1999). The fact that belief in efficacy was a reason for parents choosing the approach emphasises the need

for the SRP to be properly evaluated and for research to be conducted into the kind of children with whom this approach works best.

A large number of families were attracted to the Program because of its positive attitudinal component. The fact that parents value this aspect so greatly indicates the importance of professionals and support groups presenting a positive picture of what can be achieved by children with autism throughout their lives. This must also be tempered, however, with a realistic impression of the difficulties they will have.

When parents came to implement the Program they were very confident about their ability to use the Son-Rise techniques. Howlin (1998b) notes the value of parents having such faith in their own ability to help their child, as long as this is combined with realistic goals. Parental confidence was highest for 'joining' and 'accepting' and lowest for 'maintaining the 3Es' (energy, excitement and enthusiasm) and 'being creative'. It would therefore be advantageous for initial training to focus on these areas of lower confidence, although perhaps difficulty in maintaining the 3Es is inevitable for parents combining work, family life, and intervention with their child. The correlation found between confidence and total hours spent on intervention was interesting, although it could not indicate the direction of the relationship, i.e. whether parents became more confident because they were doing more hours or whether they did more hours because they were confident. This, and other issues related to technique use, will be explored further in the interview study, reported in the next chapter, which will also explore in more depth parental views on running the Program. The present study found that confidence in the latter area was somewhat lower than confidence in using the techniques, suggesting that this may be another area meriting greater attention in training. The interview study examines the difficulties parents had in this area, and ways in which they sometimes overcame these.

Although the parents provided training for volunteers relatively frequently, uptake of ongoing training by the parents themselves was relatively poor. Around half of the families never used the support services, and only a third attended the Maximum Impact advanced training. In addition very few parents received feedback on their use of intervention techniques from their spouse. This suggests that some families might well benefit from a higher level of feedback and supervision, and indeed about a third of the parents felt that the way in which they had

implemented the techniques had limited the effectiveness of the Program. Several parents also commented on the need for home visits by trained Son-Rise staff to be more readily available in the UK. It is likely that the SRP is one of the more difficult interventions to apply without regular supervision, as it is not highly structured and documented, and does not have easily measurable targets – qualities which aid the implementation of interventions like the Lovaas approach in a low-supervision environment (Sheinkopf & Siegel, 1998). Where ongoing training was used it does seem to have been beneficial. The Maximum Impact course significantly increased the confidence of the parents who attended it. Parents also commented that it helped raise their motivation, important for parents who may be working long hours with their child. The interview study to be reported next allowed the parents' experience of both the Start-Up and the Maximum Impact course to be looked at in much greater depth.

Parents who had used the support services were found to have used the Program for a greater number of hours each week. Again, this correlation cannot indicate the direction of the relationship. Perhaps using the Program for more hours meant that more incidents arose requiring advice, or perhaps talking to the Option Institute staff gave parents the motivation required to increase their number of hours. Greater uptake of support services was also correlated with a perception of high efficacy. Again the direction of this association is unclear i.e. whether parents used the support services more because they felt the Program to be effective and thus felt confident talking about their efforts, or whether advice given by the Option Institute helped parents to feel more effective as therapists.

Effects on the family were also examined, and overall the SRP could be summed up as making family life happier but more difficult. In Q2 and Q3 around half of the parents noted drawbacks for family life, the most common being that running the Program meant that they had less time to spend with their spouse and other children. Both the proportion noting drawbacks and the type of drawbacks noted were much the same in Q2 and Q3 suggesting that there were few changes in family effect over time. The fact that duration of Program was not significantly related to either positive or negative effects on the family also supports this interpretation. It may be, however, that longitudinal effects would have been found had the duration of the study been extended.

Although running a Program made family life less stressful in some cases, it was equally likely to make it more stressful in others. This is somewhat similar to Hastings & Johnson's (2000) finding that parents engaged in behaviour modification programmes for young children with autism had the same levels of stress as families of children with autism who were not involved in this intervention. The fact that in the present study stress was not significantly correlated with personal hours, total hours or program duration again corresponds with Hastings & Johnson (2000) who found that stress within a sample of families using the Lovaas approach was predicted by psychological rather than programme variables. It is encouraging to find that in the present study, despite stress, the majority of families found that it made their lives happier. This was particularly the case when there were few financial difficulties caused by running the Program.

Links were found between low family stress/high level of happiness/perceived benefits for the family, and parental perceptions of high program efficacy. Again this is in line with Hastings and Johnson's (2000) findings of a negative correlation between pessimism and a belief of high intervention efficacy in parents involved in the Lovaas approach. There are a number of possible explanations for the findings of the present study:

- The child had learnt new developmental skills, making interactions between family members less frustrating.
- Parents with lower stress can be more focused when they are in the Son-Rise playroom, and thus get better results.
- Parents' frustration at the lack of improvement in their child negatively affects family interactions.
- The 'happiness is a choice' philosophy of Son-Rise encourages a positive view to be taken towards both the child's abilities and effects on the family.

In the next chapter, interview data will be reported which allows expansion of these findings related to family effects, looking in particular at the situations in which drawbacks occur, how families cope with these, and why running the program might also make family life happier. This study also looks specifically at the effects of intervention involvement on the parent who is the primary therapy provider.

Around half the parents in Q3, one year on from the Start-Up course, felt that the SRP had been very beneficial for their child, with the other half perceiving it as having been slightly or moderately beneficial. Surprisingly, this efficacy rating was not significantly correlated with total hours of intervention, a finding which runs contrary to the findings of the Lovaas (1987) study, although it is in line with the findings of Sheinkopf and Siegel (1998). A possible explanation is that parents generalise their skills to interactions outside of formal treatment sessions, informally extending intervention hours and making the number of intervention hours reported somewhat misleading (Sheinkopf & Siegel, 1998). Despite the lack of connection between therapy hours and efficacy in this study, many parents nevertheless felt that their Program would be more effective if they used it for a greater number of hours each week.

There were a number of other surprising findings. There was, for instance, no correlation between perceived efficacy and the child's age, again contrary to previous suggestions that intervention is more effective with younger children (Bristol *et al*, 1996; Dawson & Osterling, 1997; Trevarthen *et al*, 1998). There was also no significant correlation with program duration. These findings are somewhat unexpected, but it may be that interactions between variables made it more difficult to detect the effects of any single one of them. For example, it may be that if age were to be controlled, total hours would be found to correlate significantly with efficacy. Another possible explanation is that there are other factors not measured in this questionnaire, such as the extent to which the intervention was implemented as designed (intervention fidelity), which also determine efficacy (Birnbauer & Leach, 1993; Green, 1996; Kerr, 2000).

The sample on which data were collected was too small to test statistically whether parents of children with autism perceived the Program to be more effective than did parents of children with autistic tendencies. The Program did, however, appear to be perceived as less effective by parents of children with learning difficulties. This does not mean that the progress that did occur was not valued by parents, nor does it suggest that Son-Rise is not appropriate for these children. Learning difficulties are often associated with a poorer outcome in other interventions, such as the Lovaas approach (Lovaas, 1987), and there is no a priori reason to suggest that this pattern would be any different in relation to the SRP.

Eye contact and social interaction were the most common areas of progress noted, followed by language. This was reported in both Q2 and Q3, suggesting longitudinal stability in the developmental areas for which the program was considered most effective. Parental reports of the efficacy of the SRP in developing eye contact and increasing sociability have been noted in other studies (e.g. Jordan, 1990; Lynch, 1996). Although it is not clear which specific technique or combination of techniques led to this progress, the current finding adds to the body of research showing that interaction involving imitation of a child with autism can increase eye contact and social responsiveness (Dawson & Adams, 1984; Dawson & Galpert, 1990).

The most common area of development where progress was less than anticipated was language. There are several reasons why this might be the case. Firstly, it may be a reflection of the stage that parents were at with their SRP. They may have been emphasising the accepting and joining side of the approach and perhaps in later months would have moved on to challenging their child more in the area of language. Having said this, some parents felt that their child was not making as much progress as hoped because they were challenging too much rather than too little. Another possibility is that as it is currently formulated, the SRP may be more effective, for some children at least, in developing social interaction than language (Lynch, 1998). This may not be unique to the SRP, as similar differential outcomes have been found with other approaches (e.g. Anderson *et al*, 1987; Moore & Bailey, 1973). It is relevant that one of the four parents who did not implement a Program also commented that their child's language progress had been less than they would have hoped for during the time from Q1 to Q3. Yet another possibility is that because language is made up of many different components parents are uncertain of the developmental sequence it should be taught in, and therefore find it difficult to teach. This is an uncertainty which may also affect progress in other developmental areas (Jordan, 1990). Jordan *et al* (1998) have also hypothesised that some interventions - and it seems likely that the SRP is one - lead to greater spontaneity and independence in communication but slower acquisition of speech whereas more structured interventions - such as Lovaas - lead to earlier vocalisations but less spontaneity.

In terms of rate of progress, 'minor but constant' was the most commonly reported pattern, followed by reports of progress that occurred in intermittent spurts. Only 4 parents noted 'constant substantial progress', suggesting that for the majority of families there will be periods



of little or no obvious development in their child. It will therefore be important for families embarking on the Program to be prepared for these times as it can be a challenge to find the motivation and patience to continue when the child's progress is not great (Huff, 1996).

## **5.8 Overview**

This study showed wide variation in both the type of children the SRP is currently being used with and the ways in which it is being implemented. It is encouraging to find that parents use the Program in ways which suit their own child and family circumstances, rather than rigidly applying the Program exclusively and intensively when this may be neither practical nor appropriate. Despite this variation it was nevertheless possible to form a profile of typical children involved and of typical patterns of use, a profile upon which any future evaluation design could be based. In terms of effects on the family, the program seemed to make family life more difficult but also happier. Most families felt that their children made at least some progress through this approach, particularly in the areas of socialisation and eye contact. There was also progress in language, although for many families this was less than they would have hoped for.

Inevitably, a questionnaire which covered so many aspects of intervention implementation was limited in the depth to which any one issue could be covered. For this reason an interview study was used to explore in greater depth issues such as school attendance, implementation of techniques and effects on family life. This interview study, Study 3, is reported in the following chapter.

## CHAPTER 6

### STUDY 3. SON-RISE PROGRAM INTERVIEWS

#### 6.1 Introduction

Chapter 5 examined a wide range of topics related to the implementation of the Son-Rise Program. This chapter describes a series of semi-structured interviews which were carried out to further explore some of these topics and assist in the interpretation of questionnaire findings. Interviews were carried out three times over the course of a year with six of the families who had been involved in Study 2.

Interview data provided methodological triangulation with the questionnaire data. When different methods of data collection yield substantially the same results, confidence in the findings increases (Cohen *et al*, 2000; Silverman, 2000). However, from the perspective that social reality is constructed in different ways in different contexts, it is unlikely that there will be a single 'truth' represented by the data collected (Coolican, 1999; Silverman, 2000). While the interview data may therefore to some extent help validate the findings of the questionnaire study, there are also likely to be differences between them. This may occur because in interviews there is the possibility of probing beyond the initial answers to open up further perspectives; there is also the chance that parents may feel more able to reveal negative feelings (May, 1993; Borg & Gall, 1989). Another factor is that interview participants were selected to represent specific features of the questionnaire sample (see below). As such, there might well be occasions when their opinions and experiences would not correspond with the questionnaire analysis since this typically reported the average of the whole sample. While the reporting of averages efficiently conveys the findings of a whole group, it may in some cases blur the experience of any one individual. It was nevertheless hoped that Study 3, reported below, would to some extent corroborate the findings of Study 2, provide greater depth of information on the issues raised there, and allow investigation of any issues which might differentially affect subgroups of families which existed within the overall sample.

## 6.2 Research topics

The interview study reported in this chapter explored the following topics:

- school attendance
- use of Son-Rise techniques
- running of the SRP
- training courses
- effects on family life
- ways in which implementation could be made easier for UK families.

A number of additional topics such as concurrent use of other interventions and accessing information on the SRP were also discussed during the interviews. However, the wealth of information provided by the parents meant that inevitably the number of issues that could be adequately explored was limited.

## 6.3 Methodology

### 6.3.1 Participants

Six parents from Scotland, who had attended the 1998 Start-Up course and had completed questionnaire one, were selected for interview. Participants were not chosen at random, as this can inadvertently produce a biased sample when selecting a small number of cases (Miles & Huberman, 1994). Rather a “stratified purposeful” sampling method was used, with participants selected to illustrate and facilitate comparison across subgroups (Cohen *et al*, 2000; Kuzel, 1992; Munn & Drever, 1990).

The six families selected were proportionally representative of the total population of families who had returned questionnaire one in terms of:

- child’s diagnosis
- child’s age
- whether the child had siblings
- number of planned intervention hours per week
- whether the parents were employed
- parents’ confidence level in interacting with their child using the SRP
- parents’ confidence level in running the SRP.

These characteristics were selected as previous literature indicated that they may be related to outcome for the child and effects on the family (Dawson & Osterling, 1997; Lovaas, 1987; Prizant & Rubin, 1999).

### **6.3.2 Family Profiles**

#### ***Family A***

Family A had a five year old son, Andrew<sup>1</sup>, who had been diagnosed with autism at the age of three. Family A were selected as interviewees in order to further explore the experience of parents implementing an SRP in a single-child family. However just before the time of the first interview Mrs. A's nephew had come to live with them. Andrew attended a special needs unit attached to a mainstream school, and the family hoped to run the Program between 5 and 6 hours per week, in the evenings and at weekends. At the time of the third interview the family were using the Program for 14 hours per week, with the assistance of one volunteer who had previously been Andrew's auxiliary helper at nursery.

#### ***Family B***

Family B had a three year old son, Billy, who had been diagnosed with autistic tendencies a month before the first interview. Billy attended a special needs nursery two days a week, and by the third interview was also attending a playgroup for an additional two mornings. The family planned to continue Billy's preschool attendance and to use the SRP with him 25 hours per week, recruiting volunteers after the first few months. At the time of the third interview they were using the Program for around 12 hours per week and had 3 volunteers, with a further 3 in training.

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<sup>1</sup> Pseudonyms have been used for all children

### ***Family C***

Family C had a five year old son, Colin, who had been diagnosed as having severe learning difficulties with motor difficulties at the age of one year and autistic features at the age of five. Mrs. C regarded Colin's autistic features as being secondary to his other difficulties. Mrs. C worked part-time but took four months leave in order to set up her Program, which she hoped to run for between 20 and 30 hours per week, with Colin's school attendance at a local special needs school being reduced to mornings only. At the time of the third interview Mrs. C had returned to work 2 days per week and the Program was being used for 20-24 hours with the assistance of 7 volunteers.

### ***Family D***

Family D had a four year old son, Daniel, who received a diagnosis of autism at age three. Daniel attended a special needs nursery 5 days a week, and initially the family planned to build up their use of the SRP to around 20 hours per week whilst continuing Daniel's nursery attendance. They tried going into the Son-Rise playroom a few times a week with Daniel, but found that he was not keen to go in. This affected Mrs. D's enthusiasm and they decided not to use the Program, although continued to use some of the techniques informally around the house.

### ***Family E***

Family E had a ten year old daughter, Emma, who was diagnosed with autism and learning difficulties at the age of five. Mrs. E, who had worked part-time, took 3 months leave to set up the SRP. Emma had previously attended a special needs school, and her attendance was discontinued for a 3 month trial of full-time Son-Rise, which the family aimed to run for 40 hours per week, with the help of 5 volunteers. After running a 30 hour a week Program for 2 months they discovered that Emma had lost the school place which they had been assured would be kept open for her return. They experienced some difficulty in getting Emma back into the school, and following this she returned to full-time attendance with the Program being used after school for 3 hours each week.

### ***Family F***

Family F had a six year old son, Fergus, who was diagnosed with autism just before three years of age. At the time of the first interview Fergus was between schools and the family planned to run the SRP for 50 hours per week, while awaiting a response from a specialist autism school where they had applied for a place. At this stage Mrs. F had 3 volunteers. After 6 months Mrs. F was running a home-based intervention for around 20 hours each week, in combination with Fergus's full-time attendance at this school. The intervention she used was a combination of Son-Rise, TEACCH and the 5-14 curriculum. She felt that Son-Rise alone lacked the academic content that Fergus needed and, while she kept the Son-Rise attitude in mind when working with Fergus, she felt that she needed to be a bit more directive with him when teaching academic skills. She thought that although the SRP had prepared her well to work with Fergus she could not risk taking him out of school to run a full-time SRP in case it proved to be ineffective. Mrs. F did not wish to participate in the second and third interview, although discussed her intervention on the phone at the time of the second interview.

A summary of the main characteristics of each family, as well as their intentions for their SRPs are shown in table 6.1, which was formed using information drawn from the first questionnaire and interview one. It shows that the families represented a wide range of child and family characteristics. All of the mothers began their SRP in the month following the Start-Up course.

Table 6.1: Profile of the six interview families

Family	A	B	C	D	E	F
Child's name	Andrew	Billy	Colin	Daniel	Emma	Fergus
child's age *	5 yrs	3 yrs	5yrs	4yrs	10yrs	6yrs
child's sex	M	M	M	M	F	M
child's diagnosis	autism unknown if learning difficulties	autistic features	autistic features SLD** motor diffs	autism	autism & learning difficulties	autism unknown if learning difficulties
age of diagnosis	3 yrs	3 yrs	5 yr	3;2 yrs	5 yrs	2;11 yrs
time since diagnosis	2 years	1 month	<1 yr	<1yr	5 yrs	3 yrs
no. siblings	1 (nephew)	1	2	1	3	1
age (sex) of siblings	7yrs (M)	4 yrs (F)	7yrs (F) 11yrs (F)	7 yrs (M)	8yrs (F) 11yrs (M) 12 yrs (M)	10yrs (F)
mother's employment	full-time	not working	on leave	part-time	on leave	not working
father's employment	full-time	full-time	full-time	full-time	full-time	full-time
confidence in use of techniques	confident	very confident	not confident	very confident	confident	very confident
confidence in running program	very confident	confident/ neutral	neutral	neutral	confident	not confident
planned hrs per week	1-10	21-30	21-30	11-20	31-40	41+
volunteers?	yes	yes	yes	no	yes	yes
planned school attendance	continue full-time	continue part-time	continue part-time	continue	discontinue	continue full-time
preschool/school	school	preschool	school	preschool	school	school
other current interventions	0	0	0	0	0	diet TEACCH vitamins
attended Maximum Impact?	no	yes	yes	no	no	no

\* the ages of children given are their ages at the time of the first interview.

\*\* SLD = severe learning difficulties

### 6.3.3 Method

The first round of interviews took place approximately two months after the Start-Up Course, and after completion of questionnaire 1. Following this the parents were interviewed again after questionnaire 2 and 3 had been returned. Only one parent from each family was interviewed (the parent who had filled in the questionnaire), in all cases this was the mother. The interviews were semi-structured, and covered many of the same topics as the questionnaires (Appendix D). Each of the interviews lasted around an hour, and was tape recorded and later transcribed. At the beginning of each interview the mother signed a consent form stating that she was agreeable to the interview being recorded. Details of this and other ethical issues relating to the interview study can be found in Appendix A.

Validity was strengthened by the use of an independent researcher who had not been involved in teaching the parents how to use the intervention. This can reduce the degree to which biases or expectations of the interviewer lead to distortions of the data (Borg & Gall, 1989).

The content and structure of the first interview was piloted on another mother who had been using the SRP for several years in order to confirm the clarity, sensitivity, and relevance of the questions. The mother commented that she felt that none of the questions was insensitive or unclear, but suggested adding a question about parents finding time for themselves, which she felt was an important issue with the SRP.

## 6.4 Methodology for interview analysis

The method of analysis used in this study was, to a certain extent, derived from the 'grounded theory' approach (Glaser & Strauss, 1967), in that concepts were gradually built up which fitted the data. However, such a 'bottom up' approach has been criticised for denying the previous experiences and assumptions which the researcher brings to the analysis process:

*"Any researcher, no matter how unstructured or inductive comes to fieldwork with some orientating ideas, foci and tools."*

(Miles and Huberman, 1984: p27, cited in Silverman, 2000)

One such influence was the findings from the questionnaire study which inevitably will have influenced the analysis of the interview data. However, Miles and Huberman (1994) suggest that



such predefined concepts can also be useful in guiding data analysis, provided they are not inappropriately imposed on the data and do not result in the data being forced too abruptly into an explanation. Mason (1994) recommends searching the transcripts for counter evidence to avoid such pitfalls.

Quotations are given to illustrate the findings of the interview analysis. These are coded with a letter A – F to indicate the family that they refer to. This is followed by a number 1 – 3 to indicate which from interview they were taken.

## **6.5 Interview findings**

### **6.5.1 School attendance**

The questionnaire findings had shown that the majority of parents had continued their child's attendance at school, and felt it to be a beneficial environment. The interview study looked further at parents' decision-making process regarding attendance. It also addressed the issue of compatibility between school and Son-Rise and how this could be maximised.

The interview data showed that parents considered the following areas when deciding whether to continue or discontinue their child's school attendance:

- the needs of the child
- the needs of the rest of the family
- the ethos of the school and the attitude of the staff towards Son-Rise
- the parent's own needs
- finance
- the situation with volunteer helpers.

The needs of the child, understandably, seemed to be the most important consideration for families and, as in the questionnaire data, the advantages of school attendance was found to play a large part in decision making. All of the families who continued their child's school attendance felt that interaction with other children at school was beneficial for their child even if they did not seem to be at the stage of forming obvious friendships. For several families the child's enjoyment of school also influenced their decision:

*"He seems really happy..he just goes in "bye bye mummy", and he comes home... and he talks about swimming, he talks about going on the slide, going to Tesco. He talks about the children in his class...and he's getting the chance to interact with children, which I feel is quite good." (B1)*

All four of the families continuing school attendance while running an SRP felt that their child was making good progress at school. One parent, Mrs. C, also commented that she felt that the teachers had a better knowledge of how to teach academic skills in appropriate sequences than she did.

In contrast, Mrs. E, the only parent to discontinue her child's school attendance to run a full-time SRP for a trial period, felt that although Emma had had some contact with the children in her class she did not interact with them greatly and was more withdrawn at school than at home. She also felt that while Emma's school was good on the whole, she had not made a great deal of progress there in the previous year.

Mrs. E, with four children, was particularly focused on the needs of the family when making her decision. She decided to take Emma out of school because otherwise she would have to run the Program in the evenings and at weekends, which she felt would conflict with the needs of the rest of the family:

*"It would be too difficult because you know we have the whole family, you know we are a whole family, we're not that we just have Emma, she's not our only child, and there would be too many practical things to do like dinners, washing and taking children out to different places they go to, and you can't stop the life of your other children." (E1)*

Mrs. B also considered the needs of the rest of the family, but in her case it meant continuing her son's part-time school attendance, so that she could organise other aspects of family life, such as food shopping, on the days when he was at school.

The attitude of the school towards the SRP also seemed to be a consideration. All of the parents who decided to continue their child's attendance felt that the school had a similar ethos to the SRP, or had teachers who knew about it and were keen to discuss goals that the family were

working on. The schools were also supportive of the families' decision to use Son-Rise. Mrs. E. in contrast, felt that Emma's school was:

*"...not even vaguely interested. Never has been any interest from the school." (E3)*

Although she felt they had been supportive when she told them of her decision to take Emma out of school for a trial period, this was belied by the fact that they did not keep Emma's place at the school open, as had been agreed.

The parents' own needs were mentioned by two of the parents, Mrs. B and Mrs. D, but as with the questionnaire data, this seemed to have less of an influence on the decision for parents than child and family needs, and the ethos of the school. Mrs. D wanted her son Daniel to continue at school so that she could continue in her part-time work which she found rewarding:

*"Although we could probably manage if we went back to me not working, at the moment I feel like we still need the extra money. Plus maybe it's selfish, but I really like working. Okay its just four hours a day, but I enjoy doing it." (D1)*

Mrs. B's decision to continue Billy's school attendance was partially related to the fact that she had had difficulty in recruiting volunteers and felt that she couldn't physically spend full days working in the playroom. In Mrs. D's case her feeling that she wasn't ready to train volunteers influenced her decision to continue Daniel's school attendance. While thoughts about volunteers were an influence, as with the parents' own needs, it seemed to be less important than the other factors.

Concurrent school attendance may potentially decrease intervention effectiveness if the child receives conflicting messages from the different approaches (Jordan, 1990; Ozonoff & Cathcart, 1998). For example, behaviour that may be deemed acceptable within the intervention may be viewed as unacceptable by the school, leaving the child confused about what is appropriate behaviour.

However, in these interviews none of the families whose children were involved in both school and Son-Rise felt that their child was getting “mixed messages” or becoming confused by involvement in both. This may be related to the fact that although they thought that the schools’ approaches were, by necessity, not identical to the SRP, they felt that there were similarities:

*“They don’t force him to do anything...There’s certain things that they all go to like swimming, and they all go to lunch, but its not a regime. They don’t sit there at the painting table and force him to paint. If he doesn’t want to paint he doesn’t paint. So it’s quite good in that respect, that it’s not working against what we’re doing.” (B2)*

Interestingly, it was the parents of the younger children who felt that their child’s school had a similar child-led ethos to the SRP. Mrs. E, whose daughter was the oldest child in the sample, felt that Emma’s school was very accepting of its pupils, but did not mention a child-led approach to teaching. It may be that compatibility between school and Son-Rise is greater with younger children, when the focus is on social rather than academic development and there is not the same emphasis on meeting targets in the 5-14 curriculum.

During the interviews some ways in which the compatibility of school and the SRP could be maximised were discussed:

- parents sharing information on the Son-Rise techniques in order to allow optimal continuity of approach between school and home wherever possible
- a two-way sharing of information between school and home about developmental goals for the child (This may be particularly helpful, as Jordan (1990) has suggested that parents involved in the SRP may be uncertain of the developmental sequence that educational skills should be taught in.)
- an overlap of staff between the two settings (for example an auxiliary from school working as a volunteer in the SRP)
- if the child was to attend school on a part-time basis, teachers rearranging the timetable so it worked to the child’s best advantage as far as possible (For example, in the case of family C, the school rearranged Colin’s timetable so that he could still have the swimming lessons they felt were important for development of his motor skills. They also made a point of letting Mrs. C know which lessons Colin was missing, so she could make up for this at home if need be.)

- if the child was to be taken out of school to do a full-time SRP, arranging a trial period during which the child's place was kept open. (This would provide continuity for the child if they returned to school, and ease pressure on the parents by offering a 'safety net' if the Program did not work out as well as expected.)

Mrs. E noted a number of issues which might be relevant for other families considering taking their child out of school. Firstly, the child may lose access to related services: Emma could no longer attend speech and language therapy and music therapy as these had previously been provided through the school. Mrs. E also felt that although a younger child could run around the playroom, Emma at 10 years old required more in the way of exercise. Taking Emma out of school meant that she no longer had access to the school swimming pool and daily exercise classes, and Mrs. E found it difficult to provide her with such frequent opportunities for exercising. The biggest difficulty was that although Mrs. E had arranged for Emma's school place to be kept open during the three month trial period, she discovered that Emma had in fact lost it, and it was only through the intervention of her local MP that Emma got back in. Jordan *et al* (1998) note that it is important for doors to be left open for return "to the fold of LEA provision", a point illustrated by the comments made by Mrs. E. She felt the situation had placed a great deal of stress on the family, and had shaken their confidence in the educational authorities:

*"I was really very disappointed all round with the lack of support and the lack of concern for the child. It was merely a numbers game. It was almost political between our region and the region in which she goes to school. I could see that was going on, like "we've got this little bit of power." I was disgusted by that attitude."* (E2)

### **6.5.2 Use of Son-Rise techniques**

Parents came across as being very knowledgeable about the Son-Rise techniques, but overall the interviews suggested that they were somewhat less confident in their use than the questionnaire data had indicated. This difference may have come about because parents felt more comfortable about revealing insecurities in the interviews.

*"I'm not particularly confident about any of them [the techniques]"* (C1)

*"It's the fear of not really knowing what we're doing ourselves, and how can we teach other people if we're not 100% sure ourselves?" (A2)*

*"Sometimes you feel inadequate, and I'm supposed to be instructing them [the volunteers]." (E1)*

Despite this the parents emphasised how much they enjoyed working in the playroom with their child. The consensus was that even though it could be tiring, it was great fun and time spent in the playroom was seen as 'quality time':

*"Well in general I'd say it's really positive. I enjoy it, it's made me feel much more connected to Colin. It's made me feel I'm involved in a positive way." (C2)*

Two of the parents, Mrs. B and Mrs. E, felt that when they began their Programs their children had an initial period of 'testing them' to see whether they would keep on joining in with the repetitive behaviour for prolonged periods of time. Two others, Mrs. F and Mrs. D, both noted that their children seemed somewhat bemused by the change in their parents' style of interaction. Mrs. F commented:

*"In the beginning he was looking at me as if to say 'is mother on drugs?'" (F1)*

As in the questionnaires, interviewed parents expressed confidence about joining with their child's activities and repetitive behaviour, and less confidence about maintaining the '3Es': energy, excitement and enthusiasm. Mrs. E and Mrs. D noted that it didn't come naturally to be "jumping about" and "shouting 'yippee!'" but commented on how effective they had found this approach in motivating their children. Several of the mothers felt that the demands of work and family life meant that they were often lacking in energy when they went in the playroom. As questionnaire data had also revealed, maintaining creativity was a difficulty:

*"I'm finding it difficult to come up with ideas to amuse him, 'cos he just cuts you off dead as if to say 'that's not funny enough, mum.'" (F1)*

*"I started to do things, you know think of things to do with a puzzle other than just putting the bits in, which is hard for me because I haven't got a very good imagination." (D1)*

Throughout the course of the interviews parents mentioned some strategies which they used to help implementation of the techniques:

- To improve creativity, one of the parents tried brainstorming outwith the room about different ways in which she could expand her son's current activities.
- When parents were having difficulty maintaining the 3Es, some tried going in the playroom for a shorter amount of time, reasoning that quality was more important than quantity.
- One parent had inspiring phrases written on a piece of paper on the wall of the playroom which she read to help maintain her motivation.
- Parents found it helpful to go back over the manual or just take a step back to remind themselves of the basic Son-Rise rules.

Parents also felt that it was easier to implement the techniques in the playroom than outwith, because it was a distraction-free environment. Having no distractions seemed to be more important for the parents than it was for the child:

*"I really enjoy it actually. Its lovely thinking that you've got no worries at all, and all you're doing is just enjoying yourself, playing with your child. It's really nice to think that you're not thinking 'oh gosh, I've got to take the washing out of the machine, I've got to get the dinner on, I have to answer the phone'. Just rid of worrying, it's nice!" (B1)*

In the questionnaires there had been a correlation between total hours of intervention provided and confidence in technique use, although the direction of this relationship had not been clear. The interview data suggested that it was lack of confidence in technique use which caused a decrease in total hours. Three of the mothers had children who enjoyed the beginning of a Son-Rise session, but did not seem keen to stay in the playroom for the full duration of it. These mothers became less confident, began to doubt their ability, and ultimately reduced the number of hours spent in the room, although there were often additional factors involved in this decision. In the case of Mrs. D, the family stopped using the SRP altogether.

*"I was thinking 'am I doing something wrong?' or 'am I giving off vibes or something'?...I did have a sort of sinking feeling and I thought 'Oh why does he not want to be in here with me?'" (D1)*

*"[Fergus tried to leave the room] constantly I would say, so obviously we're not fun enough people... I'm not too happy about it. I'm thinking, 'oh we're doing something wrong here', but I really don't know what else to do." (F1)*

*"I find it very hard to keep her in the room when I feel she really wants out...it's like forcing her to accept rather than going with her and I find that hard." (E1)*

The other three mothers increased or continued with the same number of Son-Rise hours, and all commented that their children rarely asked to leave the playroom, other than to fetch a toy.

### **6.5.3 Intervention fidelity**

In evaluation studies it is important to demonstrate that parents are maintaining 'intervention fidelity', i.e. using the techniques as laid out in the therapy 'protocol' (Bristol *et al.* 1996; Green, 1996; Jordan & Powell, 1996; LeLaurin & Wolery, 1992). Yet complexities of early intervention programs mean that there may be difficulties maintaining fidelity (Strain, 1987), a problem which has been noted both in relation to the SRP and to the Lovaas approach (Jordan & Powell, 1996).

It would be informative to examine whether parents deviate from the protocol and if so what the reasons are for this, e.g. whether it is because they feel some aspect of the intervention is ineffective or unsuitable for their child, because they have had insufficient training, or because they lack the confidence to apply specific intervention techniques.

Although this issue will be covered in depth through video analysis of a number of Son-Rise sessions in Study 4 (see Chapter 7), it seemed advantageous to initially explore whether parents intended to adhere to the therapy protocol in this interview study. As Jordan and Powell note, parents may not be aware that they are 'drifting away' from correct implementation over time, but there may be some aspects of the intervention which parents make a conscious decision to omit or change in their intervention delivery. Exploring this could assist in identifying potentially important areas on which to focus in Study 4.

Several mothers, particularly Mrs. C and Mrs. E whose children both had learning difficulties, commented that sometimes they found it difficult to let the child take the lead. Mrs. C felt that this was because Colin wouldn't often indicate anything in particular that he wanted to do:



*"I'm always a bit unsure of the balance - with Colin it's very tempting to keep offering activities or things to do... 'let's do this, let's do that, do you want to' ...because he tends not to take the initiative himself." (C2)*

In terms of changes over time, Mrs. B and Mrs. C felt that their 'directiveness' increased somewhat. They had both made a conscious decision to do this. Mrs. C mentioned in the third interview that she was happy about her increased level of requesting because she felt it was balanced by the fact that Colin was at the stage of being more able to indicate his preferences. Mrs. B had also increased her requesting over time because she felt her son was more receptive:

*"It was like [previously] there might be one opportunity [to request] in the whole session whereas now there are 10 opportunities to ask him to do things, he's much more receptive when you actually ask him to do things." (B3)*

In the case of Mrs. B and Mrs. C, although their approach changed somewhat over time, they felt that their program still fitted the protocol of the SRP, as they continued to adopt a child-led approach, dropping their suggestions and requests if their child wasn't responsive. However, there were other ways in which the families' program delivery differed more significantly from the method outlined by the Kaufmans. This was not due to any uncertainty or lack of knowledge about what the Program entailed. Rather it was a conscious decision to modify the Program to suit the child, based on the parents' experience of working with them:

*"I think as we've worked with him we've come to our own conclusions a bit and I've tried to tailor what we're doing to Colin's individual requirements, and I am aware that that's not always what would be recommended." (C2)*

For example, Mrs. C did not initially keep Colin's toys out of reach on a shelf:

*"If we'd done that at the start I don't think Colin would ever have asked for any toys. I don't think he would have the interest that this is something he could get some fun out of or he would want to use, so it would have been like the bare floor with just Colin sitting by himself." (C2)*

Mrs. B also tailored the approach to suit Billy. Rather than an exclusively 1:1 approach she sometimes involved another child, either her daughter or one of the volunteer's children, in the playroom sessions to assist in teaching concepts such as turn-taking.

Mrs. E and Mrs. F, who had the oldest two children in the sample, felt that their changes over time were such that latterly their Program was a combination of Son-Rise and 'academic teaching', rather than pure Son-Rise. Although this was partly because the parents felt that this would be beneficial for the child, Mrs. E, whose profession was a primary school teacher, said that her need to see results and the fact she found academic work easier to teach than social skills contributed to her decision to modify her program delivery:

*"I'm really aware that the real progress needs to be in socialisation, but the other side [academic] overtakes, you know if she can read this book she's achieved something, if she can do these sums she's achieved something. I can see a result, whereas the socialisation you don't see that immediately, that's a much slower process, that's why she hasn't made as much progress in the socialisation side." (E2)*

Thus, in terms of intervention fidelity nearly all of the parents made some change in their Program delivery. However, in all cases these were the result of a conscious decision by the parents, to tailor the approach to themselves and their children rather than due to a lack of knowledge about correct procedures.

#### **6.5.4 Running the SRP**

With the exception of Mrs. A and Mrs. D, all of the parents intended to recruit volunteers. Mrs. A had Andrew's auxiliary from his previous nursery to help and said that, although she might recruit volunteers in the future, she was not ready to do so in the first year of her Program.

Mrs. D felt that because they were running the Program in addition to school, recruiting volunteers would be unnecessary. She also felt that it was a role for family members:

*"I couldn't have...I know they wouldn't be strangers eventually, but I couldn't have people I didn't know coming in and working with Daniel. I don't know why, I just wouldn't feel that it was right. I feel it's up to me, and my husband and our family to help Daniel, rather than having someone else coming in and doing it." (D1)*

Those mothers who did have volunteers felt that their child benefited greatly from them, because each volunteer "brought something different" to the Program. Mrs. B, for example, felt that Billy learnt valuable social skills and independence through interacting with a number of people, rather than just being with her. Despite prior concerns, both Mrs. C and Mrs. B were pleasantly surprised at the ease with which their children accepted all the new faces, smiling and "dragging them into the playroom" when they came to the house.

As in the questionnaire data, getting enough volunteers and getting them to work the desired number of hours were major difficulties. Mrs. C commented on the "massive attempts to try and recruit volunteers with very small take-up". The families' geographical location and community involvement were clearly factors in this. Mrs. E who lived in a close-knit community and was very involved in the church found volunteer recruitment easy. Mrs. B, who had recently moved to an area on the outskirts of a city, had difficulties and commented that she would spend more time collecting and taking back volunteers than they would spend in the playroom. Both Mrs. C and Mrs. F were somewhat frustrated with the time they spent training volunteers who then dropped out or drifted away during holidays.

In the first interview all of the parents mentioned that they were somewhat apprehensive about the initial training of volunteers, and wanted to use the program themselves for a few weeks until they felt more confident about explaining the techniques:

*" I would like to use volunteers but not until I've worked with him for a couple of months myself. I don't really feel at the moment I'm in a position to train somebody for something I haven't actually done myself. I mean I know what the theory is, but I don't feel I have the practical experience of being in that room." (B1)*

Mrs. E found that making handouts helped as it gave her a concrete outline to follow and meant that the volunteers had the main points to go over. Other parents used the Option Institute books, tapes and sections of the manual, and got the volunteers to watch them work in the room. Mrs. F felt that it was also important to make sure volunteers had a realistic expectation of what was going to be involved:

*"A lot of people, their heart's in the right place, but they've got this fantasy about working with a child, but when Fergus doesn't respond or clocks them on the nose with his fist it's a different story!" (F1)*

The parents were all very aware of the value of feedback. Mrs. A commented that, unless feedback was given, both the volunteer and the child's time were wasted to some extent because neither would be getting the best out of the sessions. However, several parents were anxious about the way in which they expressed their criticisms. They did not want volunteers to feel unappreciated:

*"I think I'll probably be able to, because I do know up to a point what I'm looking for, but I'm not looking forward to it because I think it needs to be done in a very constructive way and I would hate somebody to feel that I didn't appreciate them...I think you have to be very sensitive." (C1)*

Mrs. B and Mrs. A both felt that, however feedback was given, it should be implemented as soon as the volunteers started and the purpose and method of feedback should be made clear to the volunteers from the beginning. They felt that this would mean that the volunteers would be more open to constructive criticism and would feel less self conscious about being filmed for video-feedback, as it would become routine.

Mrs. C, the only parent to hold volunteer meetings, mentioned the logistical difficulties both of giving feedback and running meetings. When a volunteer finished a session in the playroom there was often not another volunteer lined up to go in, so she had to give the volunteer feedback in the living room with Colin there, which made it difficult to focus. She also had difficulties getting childcare for Colin while she ran the meetings, because volunteers who would normally baby-sit were at the meeting. Despite this she found meetings very positive and felt that they created a "great sense of community."

While several of the mothers commented that they hoped that having volunteers would give them time to be with their other children or organise family life, both Mrs. C and Mrs. E commented that having volunteers took up more time than they had anticipated:

*"I also found that when they were all coming full-time that I was just run off my feet bringing people in you know, making them feel welcome, observing a bit, chatting to them, going over the basic rules, one coming out, trying to give that person feedback, then trying to observe the next one. I found it very, very exhausting." (E2)*

#### **6.5.5 Training courses**

In the interviews parents discussed some reservations they had had about the Start-Up course. Despite these, most parents were impressed with the incredible enthusiasm of the Option Institute staff and they also remarked on the positive atmosphere of the course which they had found very motivating. Parents felt that it was important to capitalise on this motivation by beginning a Program as soon as possible after the Start-Up course.

One concern that both Mrs. F and Mrs. C had was whether they would be able to sustain the motivation and enthusiasm that the course had given them.

*"Generally it was very positive, there was a sense of coming back feeling quite inspired, quite motivated and energised, and then I had to fit that in with the reality of the pressures on our family, the day to day life we have to lead." (C1)*

Parents differed on how they initially felt about the SRP when they went on the course. The two parents with older children who had known their child's diagnosis for a number of years both mentioned that they were somewhat hesitant and sceptical, not wanting to 'jump into' the approach until they were certain it was the right thing for their child:

*"It was a suspicion that this isn't genuine, that these people are selling a package...and it was a fear of trying and failing, not the failure for myself but the failure for Emma, you know the disappointment if this doesn't work." (E1)*

All of the parents were initially somewhat uncomfortable with the very emotional nature of the course. Some, like Mrs. A, felt it had been overemphasised and unnecessary, others like Mrs. F

and Mrs. B got used to it and found it ultimately helped them to examine their attitudes towards their child.

*"I wasn't comfortable with that, and people having to stand up and sort of you know bare their soul, weep weep groan and all that sort of stuff. I thought 'this is a bit heavy'. So I wasn't too happy about that, but as it progressed I was getting more from it. At first I thought it was very superficial, but as the days went on, I felt I could relate to it and I was actually going to be able to take something home, you know, and use it." (F1)*

Despite concerns with the emotional side, the parents on the whole felt that they gained a lot of 'good common sense' ideas of how to work with their child, regardless of whether or not they went on to run an SRP. Concepts such as the motivating effect that a parent's enthusiasm has on a child and the value of picturing how a child with autism perceives the world were singled out as being particularly helpful.

There were a number of criticisms, some of which were inevitable for a teaching course with so many participants. All of the parents who went on to run an SRP felt that they needed teaching and advice which was more individualised to them and their children. Another criticism that four of the interviewees mentioned was that they felt that there was some 'commercial pressure' put on course participants to buy the books and tapes and to pay a deposit for the Intensive course. They felt that this would be a difficulty for parents who had struggled to finance their Start-Up attendance:

*"There was a wee bit of commercial pressure to buy everything and sign up for everything and put your hands in your pocket and I felt that was maybe asking a bit much because to finance the whole course and the accommodation and the travel was a real big commitment in the first place and something I'm sure most people didn't do easily, so I think they could have toned down the commercial bit." (C1)*

At the six month stage, at interview 2, the mothers reflected on how useful they felt the Start-Up program had been in preparing them to use an SRP. Both Mrs. E and Mrs. F felt that although it had been useful in teaching the basic techniques it had not prepared them for the reality of running a program in terms of the time and energy involved.

Of the five interview families who had gone on to run an SRP two had attended the Maximum Impact course and three had not. In the questionnaire data those who had attended had become more confident. This was also reflected in the interview data. Two of the parents who had not attended, Mrs. A and Mrs. E, both felt that after six months they needed a confidence boost and to refresh their knowledge:

*"I think I just need to go back, we just need to go back and phone the Option Institute and take some direction from them to get us back on the road again." (A2)*

*"I need to refresh and renew and all of that. I need a boost, input, support, you name it." (E2)*

Mrs. B, who had attended the Maximum Impact course, had felt like this before she went. She felt that she had "Son-Rise fatigue" and was generally feeling burnt out because of the lack both of volunteers and support from her husband, but felt re-motivated when she returned from the course. She advertised for more volunteers, felt that her use of the techniques had improved, and that she was being "more present" and "really joining" her son rather than just "mirroring" his repetitive behaviour. Both mothers who had attended also felt that the course had helped their confidence because it had taught them to come up with their own solutions to difficulties they had when working in the playroom, by considering the attitudinal aspects of Son-Rise as well as the techniques. Both had also found the contact with 'like-minded families' beneficial.

#### **6.5.6 Effects on family life**

##### *Effects on the family as a whole*

The interview data confirmed the questionnaire findings in that it was the drawbacks for family life that were more prominently reported than family benefits, and as in the questionnaires there were few noticeable changes over time in parents' views. Difficulties discussed in the interviews were very similar to the questionnaire findings, with 'having less time to spend with other children' being the major concern, but with 'the family is divided' and 'other children feel left out' also featuring in parent responses.

For all the families, these drawbacks were important and seen as something to monitor and take steps to minimise. However, they were not considered to be insurmountable difficulties which prevented them from using the program. As with comments made by a number of parents who

completed the questionnaires, there was the impression that parents had done a mental 'cost-benefit analysis' and decided that the benefits to the child with autism outweighed any difficulties the family were facing.

In several of the families there was also a sense of a very positive emotional reaction to the parent's decision to use a program, with the other children pleased that the parents were doing something to try and help the child with autism. This mirrors the questionnaire finding that happiness had increased in most families.

Parents who used the Program for a greater number of hours were also more likely to say that its use had increased family happiness than parents who were using the program for fewer hours, a correlation which had not been found in the questionnaire data. Mrs. E and Mrs. A both used the Program for under 8 hours per week latterly, and felt that there had been no change in family stress or family happiness. Mrs. C and Mrs. B, by contrast, used the Program for 12 and 22 hours per week respectively and they both noted increased family happiness. Each felt that the Program had made the family feel more positively because, as Mrs. C noted, there was a "sense of purpose to what we're doing, however demanding it is."

There was a link in the questionnaire data between perceived program efficacy and family happiness, although the direction of this had not been clear. In the case of Mrs. C it seemed that the positive outcome of the Program on Colin had caused the increase in happiness:

*"I think just the whole thing of being able to appreciate what Colin can do, and see him being happier, gives us all a better sense of happiness. We're much more conscious of his personality and skills." (C3)*

### ***Effects on siblings***

Interviewees' responses indicated that drawbacks identified related primarily to age and number of other children, number of intervention hours per week, and sacrifices made by the other children. The questionnaire data had shown that, when there were young siblings, parents were more likely to mention drawbacks. This was also apparent in the interview data. Families A, B and C who had young children mentioned more drawbacks. The two families with the oldest



siblings, families E and F, felt that their other children were at an age where the Program had little effect on them:

*"I don't think it's made that much difference to them. They're interested in what they do and they're not really that bothered. My two boys are only interested in their own friends.... I'd say they were aware it was happening, but it certainly didn't have any ill effect on them, and I don't know of it having any beneficial effect either."* (E2)

In terms of number of other children, it was the families where there was only one other child that parents specifically mentioned that the other child sometimes felt left out:

*"I can't work in the room when my daughter's around because she's just deadly jealous. We went through a really bad spell with her of 'You don't love me, you never take me in the room or lock me in with you!'"* (B2)

As in the questionnaire data, families using the program for fewer hours were less likely to note 'less time with other children' as a drawback. The time of day when the program was used also seemed to be a factor, however, something which a few parents in the questionnaire sample had mentioned. If parents used the Program while the other children were out at school this seemed to keep any difficulties to a minimum. Where this was not possible problems sometimes occurred:

*"Quite often when the girls come in from school on the days when I'm not working, I'm upstairs with Colin and then you're straight into getting a meal ready and I feel like they're not getting the kind of back up or support from me that they should at that time of day."* (C2)

The sacrifices that the other children were asked to make for the SRP also determined effects on the family. For example, Colin's sisters had been asked to share a bedroom so that a room could be converted into a Son-Rise playroom. Mrs. C felt that this had increased pressure on the family.

With families B and C, the mothers noted that the drawbacks on the family had existed before the introduction of the SRP. For example, Mrs. B's daughter had been jealous of the extra

attention that Billy received at the time of his diagnostic assessment, before the program had begun. In the C family, although Mrs. C felt that using the Program divided the family, she felt that the division had been present before the Program:

*"I was going to say the fact that we don't go away for weekends together or get time off where we are just a family unit [is a drawback of the Program] but actually that is so limited anyway because of the restrictions on what you can do with Colin, what's suitable for him....We're doing the Program separately instead of other things separately." (C3)*

Parents discussed strategies they employed to minimise disruption for the family. These included:

- arranging the Son-Rise schedule to fit in with siblings' activities, e.g. by working in the playroom while the other children are at school
- having extra volunteers come to play with the siblings while parents work in the Son-Rise playroom, both to occupy the other children and to make them feel special
- explaining the purpose of the SRP to siblings, to help them understand the changes around the house and prevent them having unrealistic expectations about what the outcome would be for the child with autism
- setting aside 'quality time' with siblings
- periodic 'monitoring' of the effects on siblings
- compromising at a number of Son-Rise hours per week that would benefit the child with autism without resulting in unacceptable negative effects for the rest of the family.

In three of the families the other children in the family had picked up some of the Son-Rise techniques and used these informally around the house, such as requesting eye contact and praising verbalisations. The parents felt that this helped the interactions between the children and aided generalisation. While this informal use of the Program was appreciated by parents, having the other children work in the Son-Rise playroom seemed more problematic. Mrs. B had let her daughter help out in the playroom, but although she felt that having an extra person in the room did make it easier to teach skills such as turn taking, her daughter had difficulty in understanding the child-led aspect of the Program, something also found by Mrs. C, Mrs. D and Mrs. F in relation to sibling involvement in program delivery:

*"I've tried to get her to go into the room and play for short periods of time, but she ends up getting quite stressed and she gets angry with him then. And if she doesn't do what he wants he lashes out at her. And I think because she's a child, her voice, she screams and she's unpredictable, and he can't cope so the next thing he hits her or he nips her or he throws something at her and she storms off, so it's not a very pretty scene!" (F1)*

### ***Role of the husband***

One issue raised in the interviews which had not come up in the questionnaire was the role of the father in the SRP. Several of the mothers commented that their husband worked well in the playroom and was very energetic and enthusiastic with the child. However, all five mothers who went on to use an SRP mentioned that their husband did not spend a great deal of time working in the playroom. All said that because their husband worked full-time it was difficult for him to find enough time and energy to work in the room. Mrs. C and Mrs. B also felt it was important for their husband to spend time with the other children in the family, so that they did not feel that they were missing out on their father's attention. This also allowed the mothers to spend uninterrupted time in the playroom. While such an arrangement resulted in a somewhat divided family, such subsystems are a common way for families to function effectively (Minuchin, 1974). In this case it meant that none of the children in the family missed out on parental attention.

In some cases the husbands would have liked to spend more time working in the playroom but found it impossible due to work commitments. In family B, however, although Mr. B did not disagree with the use of the Program, he was not motivated to participate, according to Mrs B:

*"I would like my husband to do more, but he just doesn't seem bothered at the moment, which he may later on but at the moment he's not very interested. He hasn't been in the room with Billy this year that I can think of, although he's had a weeks holiday, and before that every time I nagged him, he would do it really well for a week, and then just stop and I'd think well this is not worth the confrontation, if you're not going to do it because you want to just don't bother." (B2)*

In all the families the husband was less involved in running the program than the wife. Both Mrs. C and Mrs. B found this a difficulty, and felt that they lacked much needed support:

*"I think he sees it as something that I'm doing that he will help with, and I'd like him to see it as something we're both doing as a family." (C1)*

Mrs. C and Mrs. B, who had attended some of the Son-Rise training courses alone, felt that it was important for both parents to attend the courses together. They thought this would give both parents the high degree of motivation required to run the Program and would mean that they were able to give each other the practical and emotional support required. Mrs. E, whose husband had attended the Start-Up, spoke of how much she valued the emotional support of her husband, even if his work commitments meant that he could not devote as much time to the program as he would like.

Perhaps the fact that both of the Kaufmans are jointly involved in the teaching of the SRP creates the impression that equal division of labour within the Program is an easily achievable goal, leading to disappointment in families when this does not occur. However, in most cases mothers are far more likely to be the primary therapy provider than the father (Tissot, 1999). Families considering using an intervention should bear this in mind, as perhaps it may mean that the mother should have more 'say' in choosing the type of approach to be implemented (Tissot, 1999).

### ***Effects on the mother***

The interviews also explored the effect of intervention involvement on the primary therapy provider, who in all cases here was the mother. In contrast to effects on the rest of the family, the mothers descriptions of the effects of the Program on themselves focused more on positive than negative outcomes. The most outstanding feature of interviewees responses was how rewarding parents found spending time working with their child, even those parents who had noted only slight progress or who had had difficulties implementing the techniques.

The parents of the four most recently diagnosed children commented that implementing the SRP had improved their relationship with their child, either because it had made them better able to understand how they saw the world, or because it had made them feel more accepting of their child's diagnosis. For example, Mrs. B said that although she had always been fairly accepting of Billy's autism, she had also had a tendency to compare him to typically developing children and feel quite resentful, whereas after the course she felt she could be a lot more positive about

his diagnosis, even if his symptoms were never to improve. Mrs. F also commented on the change in her relationship with her son:

*"It maybe sounds a wee bit 'I've been on the Options course', but I value him more and I appreciate him more, and I'm more understanding. I look at him sometimes and I think 'well he's got all these difficulties, but you know he's quite an amusing wee individual as well'...Before I didn't see him as that, before I saw him almost as a chore you know, or something bad that had happened in my life, a tragedy almost, and now I don't see him as that. There are difficult times, I'm not going to say there's not, but I look at him in a different light."* (F1)

Harris and Powers (1984) noted that intervention involvement may give parents a feeling of self-empowerment. Two of the mothers specifically mentioned this. Mrs. C said that using the Program had given her the possibility of being able to help Colin to progress in the way she had helped her other typically developing children when they had been preschool age. She greatly valued this:

*"It made a big impact because I have had this very overwhelming feeling of helplessness, and wanting to do something more for Colin, and I think the SRP has helped me to feel that if I do this, then whatever the outcome, we will have offered something."* (C1)

Lynch (1998) noted that the Program can be as beneficial for the parents as it is for the child because they are encouraged to change their negative ways of thinking. This was mentioned by Mrs. B and Mrs. D who both said that learning about the attitudinal side of the SRP had made them feel happier, more positive and less likely to view events or situations as problematic. However, Mrs. C noted a downside to this: she felt that the heavy emphasis on "happiness is a choice" (Kaufman, 1991) meant that sometimes she felt guilty about the fact that she wasn't positive and happy 100% of the time.

Mothers also reported that they had experienced difficulties in implementing their SRP. As with the effects on the rest of the family, these were to some extent related to the intensity of the Program. All of the mothers who used the Program, especially those who used it fairly intensively, commented that it was tiring and demanding. They felt this was particularly the case when they had been setting up the Program. Mrs. C commented that she felt "permanently

exhausted” and described the combination of going to work, running the Program and looking after the family as “ a juggling act”. Another difficulty related to intensity, but in the opposite direction, was mentioned by two mothers, Mrs. A and Mrs. E. They ran the least intensive Programs and spoke of the frustration they felt at not being able to increase their number of hours.

Cutler and Kozloff (1987) noted that, when caring for a family which includes a child with autism, the needs that are least likely to be met are the personal needs of the parents. This was reflected in the interview data. All of the mothers commented that it was difficult to find time for themselves, but that this problem had existed prior to their SRP. Several mothers mentioned the necessity of having some time to “revive” themselves, even if this was not as frequent as they would like.

Some of the mothers reported that the expectations and views of the community put some degree of pressure on them. Bronfenbrenner’s (1979) human ecology theory, described in Chapter 2, states that the family cannot be viewed as an isolated unit, but must be seen within the context of the wider community. Mrs. C and Mrs. E in particular commented on their local community. Mrs. E noted that the inverse of belonging to a tightknit community who helped raise funds and were very supportive was that she did feel some responsibility to be able to say the Program was working. Mrs. C also felt this, but commented that she was unaffected by it on the whole. Both mothers noted that sometimes members of the wider community had an unrealistic impression of how quickly progress could be achieved through the Program.

In addition to the benefits and drawbacks related to involvement in the Program, the interview with Mrs. D explored her feelings following her decision not to use one:

*“I’m happy about it. I did go through a period of thinking I’d failed him, you know, we really should be trying harder to do it, but now I’m happy with that decision because everybody, you know none of us, are thinking well we should have done it and Daniel’s not worse off for it. He’s progressing even though we’re not doing it, so it’s not like we’re holding him back.” (D2)*

She also commented that she had gained, both personally and in her interactions with Daniel, as a result of having learnt about the SRP.

### 6.5.7 Financial effects of running a Son-Rise Program

Of the six mothers interviewed two, Mrs. F and Mrs. B, whose financial situations were such that they did not need to work, felt that their family life had not been affected financially as a result of their decision to run an SRP.

Discussion of financial issues with the other three families who went on to run an SRP revealed that the difficulty had not been raising money for the big one-off expenses such as the Intensive and the Start-Up course, as in all cases fundraising by family and the community had covered this cost. The difficulty was rather a case of time versus money. While all the mothers wished to increase their number of Son-Rise hours per week, they did not have the time to do so as they could not give up work without financially compromising the family lifestyle, something which none of the mothers were prepared to do:

*"[I couldn't give up work], not without putting some financial strain on the family. I don't want them, her brothers and sisters, I don't want them growing up thinking, 'we missed out because of you.'"* (E2)

Mrs. C noted that there were expenses associated with the Program besides paying for the training courses which families might not anticipate:

*"Just little things, like paying volunteers' travel expenses, child care for the fact that Colin is home from school two half days extra, bits and pieces for the playroom, it just seems to mount up."* (C3)

Although the mothers were delighted with the fundraising efforts of friends and the community, particularly when people offered to fundraise before the parents had even asked for help, three of the mothers mentioned that they would find it embarrassing to participate in fundraising themselves:

*"I think because I've always worked for everything that I have. Why should people give me money, when I'm sitting in here, you know? I feel that it's not right that I should be asking other people for money when I probably have more money than a lot of people."* (A1)

### 6.5.8 Helping parents to implement the SRP

In the final interview parents were asked what, if anything, would make the SRP easier for them to implement. Mrs. E, Mrs. A and Mrs. C all said that having trained Son-Rise staff in the UK who could visit families every few months would help, something also mentioned by a number of parents in the questionnaires:

*"I think you need an outside help. When you are entirely on your own you begin to flounder and lose your way, well that's what I found. I would like someone coming in and saying 'no this is a better way to go' or 'yes that's the way to go'." (C3)*

Both Mrs. E and Mrs. B felt that reducing the cost of the training courses and the support services would make families more inclined to make use of them, which would be beneficial to their programs. Lack of volunteers was another aspect raised. Mrs. C suggested that a pool of trained volunteers would ease the pressure on parents, as it would mean that they would not have to spend so much time recruiting and training.

## 6.6 Discussion

This interview study sought to explore in greater depth the experience of six families who had attended the Start-Up course with the intention of subsequently implementing the SRP with their child with autism. The findings helped both to corroborate and to further explain some of the associations found between intervention use and family factors, which had been found in the questionnaire study. Although the extent to which the findings of a qualitative study such as this can be generalised is clearly limited, rigorous sampling methods were employed and this strengthens, to some extent, the claims that can be made (Platt, 1988).

A number of issues were raised in the interviews which may be helpful for families considering the approach. In relation to school attendance, the interview data validated the questionnaire findings in that, although a number of additional factors were also considered by parents during their decision-making process, the perceived benefits of school were the main reason for continuation. Conflicts of teaching methods and interactional styles between the two environments did not seem to be a difficulty. This adds to previous research showing that simultaneous implementation of two treatment models will not necessarily be confusing for children (Ozonoff & Cathcart, 1998). The data reported here suggests that a lack of conflict



between school and Son-Rise may be more likely with younger children although, given the limited number of children from different age groups involved, further research is required to confirm whether this is always the case. Parents also mentioned several ways in which school and Son-Rise could work well together, both when they are used concurrently and when there is a temporary break from school to run a full-time Program. The importance of the need for the school to keep the child's place open for return to school was emphasised, however.

Some uncertainty in how best to use the SRP techniques was another prominent feature of the findings. When the parents described their experience of implementing the techniques they seemed somewhat less confident than the questionnaire data would suggest, although they were by no means totally lacking in confidence. Despite this, the enjoyment parents gained through working with their child was apparent. In terms of intervention fidelity, several mothers noted some increase in their directiveness over time, although felt that despite this they were continuing to use a child-led approach and were not deviating from the Son-Rise protocol. However, most of the parents made some modifications to the Program, in all cases to create an approach better suited to their child, rather than as a result of lack of knowledge of the correct method of implementation.

The interviews specifically explored the parents' experience of running the Program. As has already been reported in the analysis of the questionnaire data, the mothers who were interviewed felt that recruiting volunteers had been difficult, but worthwhile; they also commented on how beneficial and enjoyable it was for their child to interact with a number of different people. Contrary to previous suggestions (PEACH, 1998), however, using volunteers was, initially at least, not as time saving as parents had hoped.

When asked about the Start-Up course it was clear that none of the parents were "jumping headlong into therapy" (Howlin, 1998b). Rather, they began the course with a fair degree of scepticism, and did not uncritically accept everything they were taught. They nevertheless drew many 'good common sense' ideas from the course materials and training.

As in the questionnaire data, comments on the drawbacks for family life were more prominent than comments on the benefits. However, parents were very aware of the situation and attempted

to minimise these disruptions as far as possible. There were no families in which mothers felt that the drawbacks outweighed the benefits of using the Program, although this view may have changed had the Program been in its second or third year, and a longer study would be necessary to establish this. There were obviously positive emotions connected with intervention involvement, particularly for the mothers, despite the fact that they found the Program tiring and demanding. It did come across though that therapy provision was primarily a role for the mother. In some cases this was due to their husband's work commitments, in some cases due to awareness of the need for their husband to spend time with the other children, and in some cases because the husband did not wish to become involved in the Program. The mother was the primary therapy provider in all of the families interviewed, even in those cases where she had hoped it would be more of a joint task. Families considering the Program should bear this in mind.

This study, as with Study 2, emphasised the tremendous variation which exists in the way parents choose to implement the SRP - in terms of intensity, concurrent school attendance, and implementation of techniques. Study 4, to be reported in the following chapter, explores the issue of variation in technique use in greater depth, and considers the implications of this for any future evaluation of the Program.

## CHAPTER 7

### STUDY 4. PARENTS' IMPLEMENTATION OF THE SON-RISE PROGRAM: A VIDEO ANALYSIS

#### 7.1 Introduction

##### 7.1.1 Intervention fidelity and therapist drift

This chapter describes the fourth study in this thesis, a video analysis of interactions over a 1 - year period of 6 mother-child pairs involved in the Son-Rise Program. This aimed to establish the extent to which the mothers implemented the SRP as it was designed, whether their use of the techniques changed over the course of a year, and if so how this related to changes in the child's behaviour.

The theme of evaluation, explored throughout this thesis, will be developed further in Study 4 in connection with the concept of 'intervention fidelity'. This was introduced in the previous chapter and defined as the extent to which an intervention is implemented as designed (LeLaurin & Wolery, 1992). In evaluating any intervention it is crucial to demonstrate a high degree of fidelity as this forms essential reliability data, increasing confidence in the research findings (Bristol *et al*, 1996; Jordan & Powell, 1996; LeLaurin & Wolery, 1992). If an intervention is found to be effective but fidelity is not assessed the possibility remains that any change in the child's behaviour was due to the implementation of extraneous techniques which were inadvertently added (Moncher & Prinz, 1991; Salend, 1983). Similarly, if behaviour change does not occur and intervention fidelity is not monitored it is impossible to establish whether the intervention was truly ineffective or whether it was simply not implemented accurately (Salend, 1983). In addition, although great store is often placed on the number of hours of intervention received by the child in an evaluation study this is meaningless without information on whether the procedures were implemented correctly (Birnbrauer & Leach, 1993; Green, 1996). It may be that in studies which recommend a high intensity of intervention delivery, a lower intensity with a higher degree of fidelity would lead to the same outcome for the child.

In previous research into interventions for children with autism information on intervention fidelity is often absent (Hemsley *et al*, 1978; Kolko, 1984; Moreland *et al*, 1982; Rogers, 1998). This is true of intervention research in disabilities in general (Gresham *et al*, 2000): reviews have found that data on fidelity to intervention protocol is reported in only around a fifth of all studies (Armstrong *et al*, 1997; Gresham, Gansle, & Noell, 1993).

If intervention fidelity in an intervention is low, this may be for one of two reasons. Firstly it may be because the therapist is uncertain of the correct techniques, perhaps due to a lack of training. Secondly it may be because, although aware of the correct techniques, the therapist has chosen not to implement them as designed. This may be because they wish to adapt the intervention to better suit themselves, their child, or the environment in which they are working. While a high degree of intervention fidelity is desirable in evaluation research, it would be wrong to suggest that it is always best for the child. For some families, changing and adapting their implementation of an intervention, thereby decreasing intervention fidelity, may well create an approach which is better suited to the individual needs of their child. This was found in relation to the SRP in Study 3, where several of the parents interviewed noted changes that they had made which they felt had helped tailor the SRP to better suit their child's abilities.

A possible reason for the lack of studies investigating intervention fidelity is that, for many interventions, it is difficult to establish what constitutes an acceptable level of fidelity. This difficulty arises because within some interventions, including Son-Rise, there is no firm basis for predicting the frequency with which a technique should be used (Jordan & Powell, 1996). For example, although one would expect the mother to imitate the child within a session of Son-Rise, there is no established frequency of imitation that must occur in order for a sufficient level of intervention fidelity to be reached. This is the case with many of the less prescriptive interventions, which do not have highly detailed protocols.

However, although it is difficult to lay down precise guidelines for such interventions, it is possible to apply more general expectations of what should occur. For example, within Son-Rise, because it is a child-led intervention it would be expected that the child would select the majority of the activities, rather than the parent. In keeping with a child-led intervention, it would also be expected that the adult would imitate most of the child's stereotypical behaviour and echolalia. Finally it would be expected that the adult would not use any techniques that were at odds with the Son-Rise philosophy of acceptance and respect for the child's choices. Such 'non-Son-Rise techniques' include selection of activities by the adult whilst the child was already occupied in their own task, physical manipulation, criticism, persisting with something that the child has objected to, and denying the child's requests (with the exception of requests to leave the playroom).

While relatively few studies have investigated intervention fidelity, those that have focused on TEACCH and Lovaas-style behavioural therapies and, on the whole, demonstrated a high level of fidelity to the intervention protocol (Anderson *et al*, 1987; Harris & Milch, 1981; Hemsley *et al*, 1978; Marcus *et al*, 1978). One exception to this was a study by

Jordan and Powell (1996) who examined the Lovaas approach and were also the first to explore intervention fidelity in the SRP. Six therapists' implementation of the Lovaas approach and seven therapists' implementation of the SRP was analysed on video. Their findings suggested that fidelity in the Lovaas approach may not be as high as had previously been suggested. This was because parents using the Lovaas approach were more child-led than would be predicted in such an adult-led, didactic intervention. This was illustrated by the fact that the child selected tasks and initiated interactions more often than would be expected. In the case of the SRP the adult was more didactic than would be predicted in such a child-led intervention, selecting tasks, issuing instructions and initiating interactions more often than might be expected.

Jordan and Powell proposed that parents using the SRP and the Lovaas approach drift over time away from the correct implementation of the techniques. In the case of the Lovaas approach they drift from a didactic, adult-led role to a more child-led approach. In the case of the SRP the opposite occurs with drift from a child-led approach towards a more didactic mode of interacting. They suggested that in the SRP this drift occurs because the adult's perception of their role as therapist is ambiguous. The teaching of Son-Rise emphasises a child-led role for the parent, but because the parent had also adopted a teaching task, the need to perform this role, and elicit an optimal performance from the child, begins to re-assert itself. In the Lovaas approach they suggested that drift occurred because a teaching role is emphasised to the parent but the natural playful parenting role cannot remain suppressed and eventually re-emerges.

Jordan and Powell proposed the term 'therapist drift' to describe this variation in the therapist's delivery of an intervention over time. Specifically, this was defined as:

*"a drift away from practices, derived from a particular theoretical approach or rationale, towards a 'mean' of behaviour in which the norms of adult-child dyadic interaction are reasserted and the differences between approaches are minimised."* (Jordan & Powell, 1996: 21)

The Jordan and Powell study into therapist drift was a preliminary investigation and as such did not utilise a longitudinal design. However, the suggestion of therapist drift made by the authors does emphasise the point that an important part of intervention fidelity is the extent to which the intervention is consistently implemented across time (Detrich, 1999). In the majority of studies into intervention fidelity noted above, parents' abilities to use the intervention techniques were measured only once and the possibility that intervention fidelity varied over time cannot be ruled out.

If therapist drift does occur in the SRP the expectation would be that there would be a decrease in the parents' use of child-led techniques over time. These techniques were

described in the outline of the SRP in Chapter 4, in the 'bonding through acceptance' section. They include imitation of the child and allowing the child to select the activities. Therapist drift might also be indicated by an increase in directive, adult-led techniques over time. Such techniques can be divided into two categories; those which form part of the SRP and would therefore be expected to be used to some extent and those which go against the philosophy of the SRP and therefore would be expected never to occur. The adult-led techniques which form part of the SRP make up the 'inspiring growth' section of the intervention, and include requesting and activity selection by the adult. However, although these techniques are present to some degree in the SRP, it is a child-led intervention and as such these more directive techniques would not dominate the interaction. For example, while some adult task selection may occur it would not be expected that the adult would select more activities than the child, although there is no firm basis for predicting an exact proportion that would be selected by each. The second group of adult-led techniques which are expected never to occur ('non Son-Rise' techniques) are listed on page 182 and include physical manipulation and denying the child's requests. If use of any of these two types of adult-led techniques increases over time this could be classified as therapist drift.

In terms of requests made by the mother, any changes in the type of request used over time might also be indicative of therapist drift (Jordan & Powell, 1996). Type of request can be viewed as a continuum from the most directive to the least directive. Instructions are the most directive because the statement does not offer the child the opportunity to express whether they wish to comply or not. Questions, suggestions and choices are less directive as they give the child more scope in determining a response to the request. Jordan and Powell's conception of instructions as directive requests and choices as child-led requests can be further expanded by adding a third type of request; the indirect request. This is when the mother makes it clear that she wishes the child to do something specific but does not use words, or uses words which do not form an explicit request. Rather than the words, it is the mother's gesture, expectant look, pause, or withholding of some action that indicates that she is requesting something. An example of this is when the mother sings a song and then pauses and looked expectantly at the child to indicate that she wishes the child to sing the next word. As the child is not explicitly being asked to do anything this type of request is arguably the least directive. While these three types of requests lie on a continuum broadly speaking, it is acknowledged that factors such as the mother's tone of voice and the number of times the request is repeated may also affect how directive the request is. All three types of request could be expected to occur in the SRP. Even instructions, the most directive, would be used although this would be on the basis that, as with any request, if the child indicates that they do not wish to comply with the request then the adult is respectful of this.

It should be made clear that while therapist drift would be indicated by an increase in the adult-led techniques described above and a decrease in child-led techniques, the two groups of techniques are not inevitably linked; child-led techniques may decrease without a corresponding increase in adult-led techniques and vice versa.

The potential for therapist drift in the SRP, to date, remains an unresolved issue, with a current lack of any substantive evidence that parents do become increasingly directive over time. However, the fact that in Study 3 several of the mothers interviewed felt that they had become increasingly directive and taken on more of a 'teacher' role over time suggests that therapist drift is indeed a possibility. Related research also supports claims of likely therapist drift. Both Trevarthen *et al* (1998) and McCollum and Hemmeter (1997) review research which suggests that mothers of children with disabilities, including autism, tend to be more directive than mothers of typically developing children, perhaps due to the fact that their children are less likely to initiate attention-sharing during social interactions. If parents do become increasingly directive during their implementation of the SRP this may be because over time the natural tendency to be directive re-emerges as a way of compensating for their child's lack of attention-sharing and responsiveness.

An alternative possibility is that although mothers of children with disabilities are more directive than mothers of typically developing children, as they gain experience of a child-led intervention, such as Son-Rise, they become more adept at letting their child take the lead, thus directiveness decreases rather than increases over time. This has been suggested by authors in relation to other child-led interventions. Hewett and Nind (1998), for example, suggested that parents and particularly teachers using Intensive Interaction may be more adult-led at the beginning of the intervention, which may be, in some cases, because their previous methods of working with the child were very directive (Taylor and Taylor, 1998). Hewett and Nind suggest that directiveness may decrease over time as the parent becomes more practiced in their use of the intervention. This has also been noted in anecdotal reports by other practitioners of the approach (Samuel & Maggs, 1998; Stothard, 1998). As the SRP is similar to Intensive Interaction it might be expected that the same pattern would occur, with parents becoming more experienced over time at allowing their child to take the lead. However, although the SRP and Intensive Interaction are similar they are not identical and any comparisons between the two must be made cautiously.

There are then three possibilities: the first that therapist drift does occur and that intervention fidelity decreases over time; the second that parents become more

experienced in use of intervention techniques over time and fidelity increases; the third that different patterns characterise changes in technique implementation over time in different mother-child pairings.

Therapist drift in the SRP may not be restricted to changes in child-led and adult-led techniques; there may be additional techniques which parents find difficult to maintain over time. For example, within the SRP parents are taught to use a great deal of praise, both when the child attempts to comply with a request and, in keeping with its child-led philosophy, in response to the child's own activities (to indicate the adult's acceptance of the child as they are). Parents are also taught to praise the child for refusing to comply with a request. Praise is given in these circumstances to reinforce the child's attempt to express their desires in an appropriate manner. While praise occurs within any typical adult-child interaction it may be that, because adults are taught to use it in the SRP much more frequently than they normally would, it is susceptible to therapist drift. Thus, although parents may begin the intervention with a very high level of praise this may decrease over time, until it returns to the level that they used before beginning the intervention. This may be particularly the case for praise given for the child's own activities and when the child refuses to comply with a request; parents may not be as accustomed to giving praise in these circumstances.

The '3Es' – energy, excitement and enthusiasm – may similarly be prone to therapist drift. Within the SRP parents are taught to increase their '3Es' to a level far greater than in their previous interactions with their child. In Chapters 5 and 6 a number of parents participating in the Son-Rise questionnaire and interview studies reported that this was the technique which they found the most difficult to implement. This suggests that it might also be one of the techniques most prone to therapist drift, although it is probably also the most problematic to measure, as it is so difficult to quantify.

While praise and the '3Es' are techniques which may be prone to therapist drift in the SRP, it is equally possible that as parents become more skilled at implementing praise and the '3Es' over time, as they gain experience of the SRP, intervention fidelity could increase rather than decrease over time.

In summary, there are two fundamental areas to be explored in greater detail. Firstly, there is a need to establish what parents' initial level of intervention fidelity is when they implement the SRP, although the difficulties in quantifying fidelity in this particular intervention are acknowledged. Secondly, there is a need to explore any therapist drift. Do parents move away from the correct implementation of the SRP over time, as indicated by a decrease in child-led techniques, praise and the '3Es' and an increase in



adult-led techniques? Or does the reverse pattern occur as parents gain more experience in their implementation of the Program? Alternatively, perhaps a totally different pattern characterises changes in technique implementation over time within individual mother-child dyads.

Note that the concept of ‘therapist drift’ explored within this study is essentially one of decreased intervention fidelity over time, with movement away from the correct implementation of the Son-Rise techniques - high levels of child-led techniques, praise and the 3Es, and the low levels of adult-led techniques - towards levels found in more typical mother-child interactions.

This is, though, slightly different from the definition of therapist drift originally put forward by Jordan and Powell (1996). They too, viewed therapist drift as being a movement away from the intervention rationale towards the norms of adult-child interaction. However, Jordan and Powell include in their discourse analysis a somewhat different set of techniques representative of the SRP ethos, for example also including explication of subjective experiences, the absence of target behaviours and child initiations.

In addition, a further difference is that although within the current study all maternal praise is considered a SRP technique, within Jordan and Powell’s study this was true only of praise which represented ‘exaggerated and explicit feedback’ (e.g. “Oh, you gave me such a lovely look! It makes me very happy when you look at me like that!”). This was because such praise conveys the Son-Rise notions of energy, excitement and enthusiasm, and the need to provide the child with explicit explanations of events. Praise such as “Good looking!/ Good boy!” was not included as a SRP technique, and was instead considered representative of therapist drift, because it contained none of the elements described above, and instead was judged by the authors as being more akin to the type of task-extrinsic, positive reinforcement found in adult-led interventions such as Lovaas.

Jordan and Powell’s original definition of therapist drift also included the notion that any changes in the adult’s style of interaction over time could be influenced by how the adult initially conceives of their role as ‘therapist’ at the outset of the intervention: if they identify their role as a predominantly nurturing one they may move increasingly towards a child-led approach over time, whereas if they identify their role primarily as a teaching one they may move towards a more didactic approach. In this respect Jordan and Powell’s definition of therapist drift is somewhat more complex than one

emphasising simply a straightforward decrease in intervention fidelity over time. It was beyond the scope of this thesis to consider these additional complexities but it would be important to keep these effects of the child-parent relationship in mind in developing this research further.

### **7.1.2 Impact of parent training on therapist drift**

An additional area to be explored in relation to intervention fidelity and therapist drift is the impact of parent training (Detrich, 1999; Sterling-Turner *et al*, 2001). As noted in Chapter 4, there are a number of different types of training provided for parents, both prior to implementation of their SRP, and as an ongoing service.

Both type and timing of initial training may have an effect on intervention fidelity. The two types offered by the Option Institute are the Intensive one-week visit to the Institute for training on a 1:1 basis, and the Son-Rise Start-Up course which offers group training. Group training may offer mutual support from other parents and is more economical of the trainers' time, but it is likely 1:1 training will be more effective in the respect that it can be tailored more specifically to the needs of the individual family (Clements, 1985; Groden & Domingue, 1988). The length of time between training and commencement of the intervention may also affect intervention fidelity; families who begin their Program a long time after initial training may have difficulty in remembering exactly the correct use of the techniques.

If therapist drift is a phenomenon which does occur during the implementation of Son-Rise, ongoing parental training may help prevent it. This point was raised by one of the mothers in Study 3 who commented "when you are entirely on your own you begin to flounder and lose your way." The Option Institute offers several types of ongoing training including 1:1 intensive training at the Option Institute, 1:1 training in the home, group training at a 'Maximum Impact' advanced course, support phone calls and advice based on Son-Rise staff analysis of videotaped Son-Rise sessions. There is a general consensus that 1:1 training which involves demonstrations of correct techniques and observation of parents applying these has more impact than group or 'at a distance' teaching (Clements, 1985; Moreland *et al*, 1982; O'Dell, 1974; Schopler & Reichler, 1971a; Sterling-Turner *et al*, 2001). It thus seems likely that if therapist drift does occur, 1:1 training either at the Option Institute or in the home would be the most effective in preventing it, as both of these offer demonstrations of how to use the Program with the child and feedback based on observations of parents using the techniques. This is not to imply that the other types of training are not valuable, simply that 1:1 training might be the most useful in preventing therapist drift.

### 7.1.3 Relationship between child's behaviour and therapist drift

The focus so far has been on the parent and their application of the Son-Rise technique. However, the parent does not apply these techniques in isolation and it is important to consider how the child's behaviour affects the parents' use of the SRP.

If the parents' use of techniques becomes more adult-led over time this may not be due to therapist drift, but due to the fact that their child has become more interactive, as was the case when the Kaufmans originally used the approach with their own son (Kaufman, 1994). Such responsiveness to the child's behaviour is described in figure 4.1, 'times to 'bond through acceptance' and times to 'inspire growth' (Chapter 4 – p81). If the child is particularly withdrawn during a Son-Rise session the mother may 'bond through acceptance' by imitating the child more and making fewer requests than she normally would. Such a withdrawn state in the child may be characterised by stereotypical behaviour, echolalia, and a low frequency of eye contact, physical contact, appropriate vocalisations and laughter. In contrast, when the child is particularly interactive the mother may request more and imitate less. On these occasions the child may have a high frequency of eye contact, physical contact, appropriate vocalisations and laughter, and show a lower frequency of stereotypical behaviour and echolalia. If the child gradually becomes more interactive over time the adult would move to 'inspiring growth' more and 'bonding through acceptance' less.

Such a relationship between the child's behaviour and the mother's use of techniques was commented on by two of the mothers in Study 3 who felt that although their level of requesting had increased over time, one of the reasons for this was that their children had become responsive and more able to indicate preferences. Exploring the child's behaviour over time in parallel to examining any changes in the mother's technique use over time is essential to understanding the nature and significance of any 'therapist drift'.

The exploration of fluctuations in the child's behaviour over time in relation to the mother's techniques will allow suppositions to be made about possible relationships between the two. Conclusive evidence of a relationship cannot, however, be shown by any naturalistic observation study such as the one to be reported here. While an increase in a specific behaviour from the child may correspond to an increase in the use of a technique by the mother, the two are not necessarily related – it may simply be coincidence that both have increased. It seems likely though that the longer the period over which a pattern of fluctuations in the child's behaviour corresponds with fluctuations in the mother's techniques, the more chance there is that there two are in some way linked.

Even where the child's behaviour does seem to be strongly linked to the mother's techniques this can give no indication of causal direction. For example, if an increase in the child's use of spontaneous words appeared to correspond with an increase in the mother's use of requesting this would not necessarily mean that the change in the child's behaviour has caused the change in the mother's technique use. The reverse may be true; a high level of requesting by the mother may take the pair's activity in a new direction, prompting the child to talk more. Alternatively, there could well be other factors causing both the child's behaviour and the mother's use of a technique to change over time. When exploring the relationship between the child's behaviour and the mother's techniques, it is important to bear these issues in mind in interpretation of any patterns suggesting connections between the two.

## **7.2 Research questions**

This longitudinal study explored intervention fidelity and therapist drift in the SRP by filming six mother-child pairs during SRP sessions every two months over the course of a year. The questions it sought to answer were:

- (1) Do the mothers have an initially high or low level of intervention fidelity?
- (2) Is this related to time since initial training?
- (3) Do mothers show a pattern of technique implementation suggestive of therapist drift over one year of the SRP, as shown by an increase in frequency of requests, use of directive types of request, and adult task selection, and a decrease in imitation of the child, child task selection, praise, and the 3Es?
- (4) Does ongoing 1:1 training have any impact on the occurrence of therapist drift?
- (5) Do changes in the child's behaviour over the course of the year appear to be related to the mother's implementation of Son-Rise techniques?

## **7.3 Methodology**

### **7.3.1 Participants**

Six mother-child pairs were involved in this study. This sample constituted all of the families in the Lothian region who attended the SRP Start-Up course in January 1998, and who had decided to run an SRP at home with their child. Four boys and two girls participated in the study and table 7.1 shows the child characteristics<sup>1</sup>. It should be noted that two of these children, Kevin and Laura, were brother and sister. Therefore throughout the study reference will be made to six children but only five mothers. To avoid confusion 'pair K' will be used to refer to Mrs. K working with Kevin and 'pair L'

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<sup>1</sup> Pseudonyms were used for all children in this study

to refer to Mrs. K working with Laura. There was a wide variation in the age of the children, with age at the first Son-Rise filming session ranging from 2 years 10 months to 10 years 2 months.

Table 7.1: Profile of study participants

Pair	G	H	I	J	K	L
child's name	George	Harry	Ian	Jill	Kevin	Laura
child's sex	M	M	M	F	M	F
child's age*	5yrs 5mths	4yrs 3mths	4yrs 8mths	2yrs 10mth	9yrs 10mth	7yrs 2mths
child's diagnosis * *	autism	autism	autistic tendencies	autistic tendencies	autistic tendencies	autistic tendencies
additional diagnosis * *	develop- mental. delay	none	pervasive communication disorder	develop- mental delay	mild to severe learning difficulties	none
age at diagnosis	3yr 11mth	2yrs 6mth	3yr 6mth	1yr 7mth	4yr 9mth	~ 4 yrs

\* at first filming session

\*\* by paediatrician, clinical neuropsychologist or educational psychologist

Below are short descriptions of each child involved in the study. These detail their school attendance along with typical verbal and play behaviour.

*George*

George attended a mixed-needs special school on a full-time basis, with the SRP used in the evenings and at weekends. At the beginning of the study George had a vocabulary of around 200 words, which he used to express his wants and needs, but rarely to comment on his activities or surroundings. He also displayed both immediate and delayed echolalia and used long sequences of word approximations which seemed to be indistinct echolalia. He showed some stereotypical behaviour such as repeatedly twirling a toy in his hand, as well as longer repetitive routines and a strong attachment to some toys which he objected to other people touching.

### *Harry*

Harry attended a mixed mainstream/special needs children's centre one morning a week, with attendance discontinued halfway through the study. Aside from that the SRP was used on a full-time basis, for around 25-30 hours per week. Throughout the study Harry's communication consisted mainly of babbling-like utterances, with occasional use of the first letter or syllable of a number of words, as well as few full words. He displayed very occasional hand flapping stereotypical behaviour.

### *Ian*

Ian's parents discontinued his attendance at nursery before beginning an SRP and used a full-time SRP, for around four hours per day. Unlike the other families in the study, they ran their Program without the assistance of volunteers. Ian had a vocabulary of several hundred words, although both his comprehension and his expression of language were low for his age (table 7.2 – see below).

### *Jill*

Jill, the youngest child in the study, attended a nursery three mornings a week, with the SRP being used the remainder of the time, for an average 20 hours per week. Like Harry, Jill's communication consisted of babbling-like utterances with occasional use of the first letter or syllable of a number of words, as well as a few full words

### *Kevin*

Kevin was the oldest child in the study. He attended a mixed needs special school with the program being used after school and at weekends. Echolalia, both immediate and delayed, made up a large part of his vocalisations, but he often maintained good eye contact while speaking. He also often displayed hand flapping and finger flicking stereotypical behaviour.

### *Laura*

Laura attended a language unit attached to a mainstream school, with the SRP being used in the evening and at weekends. Formal language assessment proved to be impossible (see below) but speech therapy reports indicated that she had a wide vocabulary, with expression and comprehension much greater when language was part of a familiar routine. In contrast to the other children in the study who initiated a range of games and activities, Laura spent the vast majority of time in the playroom very focused on drawing pictures.

All six children were given a test of cognitive ability (the performance subtests of the Revised Wechsler Preschool and Primary Scale of Intelligence (WPPSI-R) or the Bayley Scales of Infant Development (2nd edition) and social maturity (the Vineland Adaptive Behavior Scales) at the beginning of the study to provide a broadly-based description of each child's current abilities. These are reported in table 7.2, along with the results of language assessments, where these were available. Language measures were normally based on the Reynell, with data collected by speech and language therapists who were already working with the child on a regular basis. The WPPSI-R was chosen for assessment as it has been suggested that many other IQ tests, such as the Stanford-Binet, which are heavily verbally loaded, may be unsuitable for a high proportion of children with learning difficulties (Sattler, 1982). The Bayley Scales were chosen over other infant development scales such as the Merrill-Palmer for use with the younger children because of its high reliability and suitability for young children with developmental delay (Anastasi & Urbina, 1997; Sattler, 1982).

In all four cases where the WPPSI-R was used and in three cases where the Reynell Developmental Language Scale was used the children would not engage with the testing materials for a sufficient length of time to complete the number of items necessary to produce a formal test result. In these cases results are given for the portion of the test which were completed. As the tests were intended only to provide a fuller description of each child, and were not to be used for purposes of matching, access to complete test data was not central to the design of the study. The fact that a formal testing session was not possible in itself adds to the description of the child, however.

Table 7.2: Results of developmental assessments of participants

Child	George	Harry	Ian	Jill	Kevin	Laura
<b>Cognitive test</b>	WPPSI-R	Bayley	WPPSI-R	Bayley	WPPSI-R	WPPSI-R
<b>Age at administration</b>	5;5 yrs	4 ;3 yrs	4;7 yrs	2;6 yrs	9;1 yrs	7;4 yrs
<b>WPPSI-R/ Bayley age equivalent</b>	3;6 yrs *	2;0 yrs	below test lower limit of 3;0 yrs*	0;10 yrs	3;6 yrs*	5;9yrs*
<b>Age at VABS** administration</b>	5;5 yrs	4;3 yrs	4;10 yrs	2;3 yrs	9;1 yrs	6;9 yrs
<b>Communication age equivalent</b>	1;4 yrs	1;5 yrs	1;8 yrs	1;3 yrs	1;7 yrs	2;10 yrs
<b>Daily living skills age equivalent</b>	1;11 yrs	2;9 yrs	2;1 yrs	1;1 yrs	3;1 yrs	4;1 yrs
<b>Socialisation age equivalent</b>	1;7 yrs	1;10 yrs	2;8 yrs	0;11 yrs	2;3 yrs	3;3 yrs
<b>Language test</b>	Reynell ***	Reynell	Reynell	Bayley	Reynell	Reynell
<b>Age at administration</b>	5;9 yrs	4;3 yrs	4;7 yrs	2;6 yrs	9;6 yrs	6;10 yrs
<b>Result</b>	child did not complete sufficient number of test items to allow age equivalent assessment	child did not complete sufficient number of test items to allow age equivalent assessment	comprehension age = 2;1 yrs expressive age = 1;10 yrs	language age = 1;0 yrs	comprehension age = 1;3 yrs expressive age = 1;10 yrs	child did not complete sufficient number of test items to allow equivalent assessment

\* full test score cannot be given, as child did not complete sufficient number of test items. Reported MA based on object assembly subtest only (except Laura where MA based on average of object assembly and picture completion subtest scores.)

\*\* Vineland Adaptive Behavior Scales

\*\*\* Reynell Developmental Language Scales - in all cases carried out by the child's speech and language therapist.



**7.3.2 Training in SRP techniques received by mothers**

All mothers attended initial group training at the one week SRP Start-Up Course in London, with the exception of Mrs. H whose husband attended and then taught her the techniques. Table 7.3 indicates the time after training that the mothers began implementation of their SRP.

Table 7.3: Time between initial ‘Start-Up’ training and Son-Rise Program implementation

Mother	Time between training and Program implementation
G	1 month
H	< 1 month
I	3 months
J	6 months
K/L	13 months

Table 7.4 gives details of ongoing 1:1 training that the mothers received during the course of the study, either during one week ‘Intensive’ training at the Option Institute in Massachusetts, or during a home-training visit by a Son-Rise trainer.

Table 7.4: Ongoing 1:1 training received by mothers

Mother	1:1 Training received during study
G	None
H	Visit from Son-Rise trainer between sessions 6 & 7
I	None
J	Option Institute visit between filming sessions 5 & 6
K/L	Option Institute visit between filming sessions 2 & 3 (with Kevin) Option Institute visit between filming sessions 4 & 5 (with Laura) Visit from Son-Rise trainer between sessions 6 & 7 (for both children)

In addition to the 1:1 training, all mothers except mother I used support phonecalls to the Option Institute throughout the study and all mothers attended group training at the Maximum Impact advanced course.

Four of the five mothers used the SRP with their child for the 1-year duration of this study, with most continuing their implementation of it after the study had ended. The exception to this was Mrs. I who changed from the SRP to the Lovaas approach during the study, because she felt that Ian was not being challenged enough within the SRP. The final two filming sessions (6 and 7) were therefore of Mrs. I using the Lovaas approach. Although this meant that the issue of therapist drift could only be examined over 8 months rather than 1 year, it was felt that this would be a sufficient length of time to observe any emerging patterns. The final Lovaas sessions were also included in the

analysis to allow consideration of how Mrs. I's implementation of the SRP differed from her use of the Lovaas approach. Although Mrs. I received no ongoing Son-Rise training, she did receive 1:1 training in the Lovaas approach before session 6.

### **7.3.3 Procedure**

At the beginning of the study the mother signed an informed consent form. Details of this and other ethical considerations related to the research reported in this thesis are described in Appendix A.

Each mother-child pair was filmed in their Son-Rise playroom once every two months over a one year period (total of 7 filming sessions per pair). The first Son-Rise filming session took place within one month of the family beginning their SRP. To control for variation in the child's behaviour throughout the day filming sessions always took place at the same time of day and on the same day of the week wherever possible, allowing for unavoidable changes due to illness, and changes in the parents' work schedule. Mothers were instructed to behave as they normally would during a Son-Rise session. Each filming session lasted around 30 minutes, with the intention of analysing the middle 20 minutes. This allowed for the mother and child to have 5 minutes at the beginning, to become comfortable with the presence of the observer and camera in the room, and 5 minutes 'cool down' time at the end when the mother may have been aware that the session was coming to a close.

The same observer filmed every session, so that the child would not be distracted by a new face during the one year period. The observer and camera were positioned in an unobtrusive location in the corner of the playroom, and movement was kept to a minimum except to quietly change location when the pair turned away from the camera. Although many of the playrooms had two-way mirrors on the doors, potentially allowing filming to be done less obtrusively from the outside, this would have meant that facial expressions were obscured when the pair turned away from the door.

The observer stayed as still and quiet as possible during the session, to avoid causing distraction. Attempts by the child to interact with the observer were ignored, as a means of encouraging the child to return to the interaction with their mother. In order to encourage the child to remain focused on the interaction with the mother, the observer attempted to minimise any interaction with the child when arriving at the house before the filming session began, although sometimes this was unavoidable, for example if the mother was not ready to go into the playroom straight away.

As it has been suggested that a somewhat familiar adult may sometimes attract less attention and interest from children being filmed (Hauck *et al*, 1995), the observer met the children before the first filming session, and filmed a 30 minute mother-child play session outwith the Son-Rise playroom, to help the pair become accustomed to her presence and the camera. As a number of the families had CCTV cameras installed in their playrooms, for the purpose of giving volunteers feedback, the children were already accustomed to being filmed.

#### **7.4 Methodology for video analysis**

Twenty minutes of each session was analysed using the Observer Video-Pro, a software package which allows frame-by-frame analysis of events and interaction, and hence a potentially high level of accuracy in data analysis (Noldus Information Technology, 2000). The software is designed for use with digital video files, and allows rapid review of all similarly coded episodes – something not possible with traditional analogue video. Again this helps to increase accuracy by allowing close comparison of all instances of a any given behavioural category.

The process of conducting video analysis using the Observer Video-Pro is as follows: firstly each behavioural category is assigned a 'keycode' – a single key on the computer keyboard. In the case of behaviours where a measure of duration is required one keycode is used to indicate the beginning of a behaviour, and another keycode to indicate the end. Each videotaped session is then converted into a digital file. The video files of each mother-child session are reviewed multiple times, checking for all instances of one particular behaviour on each viewing (e.g. imitation). Every time the behaviour is observed the relevant keycode is pressed. This creates a record of the behaviour observed and the precise time-point in the video at which it began and ended. The Observer system integrates the data generated from each viewing of the video file to produce a single record of events. The record shows the sequence of all coded behavioural events from the beginning of the video to the end. This process is repeated for each videotaped session. The Observer system also contains a basic statistical analysis package which can produce measures such as total frequency and duration of each behaviour contained for each videotaped session.

Sessions were analysed out of sequence to minimise effects caused by observer expectancy. Continuous sampling analysis was used, with all occurrences of the 11 behaviours listed below being noted. This sampling method allows development of an exact record of behaviour and preserves more information than time sampling, i.e. coding at set intervals (Caro *et al*, 1979; Martin & Bateson, 1993).

As there was no pre-existing behavioural categorisation system which was suitable for exploration of the research questions outlined above (p.91), the development of a new coding scheme was necessary. This scheme was formed initially from the descriptions of the SRP both in the training manual (The Option Institute and Fellowship, 1996/1997) and in several of the case studies written by the Kaufmans (1981, 1994). The *maternal* behaviours chosen were those described in the Son-Rise literature as conveying either 'bonding through acceptance' (child-led techniques) or 'inspiring growth' (adult-led techniques). In addition, a category of 'non Son-Rise techniques' was formed from behaviours which were described in the Son-Rise literature as contrary to the ethos and philosophy of the Program. The categories of praise and laughter were also included, in order to investigate the possibility that the frequency of these were susceptible to change over time. Laughter was included as a maternal behavioural category as an alternative to the '3Es' (energy, excitement and enthusiasm), for the reasons outlined on p.92.

The *child* behaviours chosen were derived from the Son-Rise literature and in addition from literature describing the behaviours of children with autism in general (e.g. Trevarthen *et al*, 1998; Howlin, 1998a; Wing 1996a). Child behaviours included in the categorisation scheme were those that were interpreted in this combined body of literature as conveying either an interactive state (e.g. physical contact, eye contact, laughter) or a withdrawn state (e.g. echolalia, stereotypical movement). Preliminary definitions of both the maternal and child coding categories were formed from the descriptions given in the literature, augmented by the author's own impressions of these behaviours from the filmed sessions.

The draft coding scheme was piloted on segments of 3 of the 42 videotaped sessions, and all instances in which there was some uncertainty over how to apply the coding system were noted. Further consideration of these difficulties led to the expansion and/or clarification of the definitions of each behavioural category. Altogether 11 categories of behaviour were coded: 5 for the mother, 5 for the child, and 1 for task selection (both mother and child). These behavioural categories were mutually exclusive, although they could co-occur in time, either wholly or partially. The categories are described in brief below, with a more detailed description of each behaviour given in Appendix E.

#### **7.4.1 Mother's behaviour**

##### ***(1) Imitation***

All instances in which the mother copied the child's actions or vocalisations, were coded as imitation. Excluded from the category were instances where the mother repeated the child's vocalisation but for the purpose of expansion or clarification rather than imitation. These seemed to have a teaching purpose rather than being imitative.

## ***(II) Requests***

Instances in which the mother asked the child to do something were coded as requests. This category was further sub-divided according to whether the adult issued a question/suggestion/choice, a direct instruction, or an indirect request. An indirect request was coded when the mother made it clear that she wished the child to do something specific but either did not use words or used words which did not form an explicit request. An example of this is when the mother misses a word out of a song that she is singing and looks expectantly at the child to indicate that she wishes the child to say the word.

Occasions where the mother repeated the request before the child had complied with the original statement were noted and two measures taken: (a) the number of original requests (reflecting how many behaviours the child was asked for) (b) the number of original requests plus the number of repeated requests (reflecting how many times the child was asked to say or do something).

## ***(III) Non Son-Rise techniques***

Instances in which the mother used behaviour which was at odds with the Son-Rise philosophy of acceptance and respect for the child's choices were coded as Non Son-Rise techniques. These included:

- criticism of the child
- physical manipulation – where the mother physically moved the child against the child's will
- persisting with something that the child has objected to
- selecting a task when the child was occupied in their own task
- denying the child's request  
(excluding requests to leave the room/get the key for the door, or requests that were impossible for the mother to fulfil).

## ***(IV) Praise***

This category covered behaviour in which the mother commended the child's activity, vocalisation, eye contact, or any combination of these. The praise did not have to be verbal. The mother could clap or cheer, as long as it was clear that this was directed towards what the child has just said or done. A distinction was made between praise given to the child for their own activity, praise given to the child for attempting to comply with a request from the mother, and praise given for the child not attempting or refusing to

comply with the mother's request. Thanking the child was included as praise, e.g. "thank you for looking in my eyes", as this is a common form of praise within the SRP.

#### ***(V) Laughter***

The '3Es' were identified in the introduction as being a useful behaviour to analyse. However, it was anticipated that this would be difficult to code reliably, as coding would have to be based largely on subjective opinion. It was thus decided to code for instances of laughter as an alternative. Although laughter does not encapsulate every aspect of the '3Es' it was considered to be the nearest objective measure, as both encompass an element of enjoyment. The differences between 'laughter' and 'energy, excitement and enthusiasm' are though acknowledged, in particular the fact that laughter is something too spontaneous to be regarded as a technique.

#### ***Approaches to the camera***

Behaviours used by the mother to draw the child away from the video camera, such as selection of new tasks and non-SRP techniques were not included in the analysis. The presence of an observer in the playroom is not part of the natural Son-Rise environment and as such, these specific behaviours could not be considered representation of a 'normal' SRP session.

### **7.4.2 Child's behaviour**

Spontaneous behaviour as opposed to behaviour requested by the mother was coded, in order to reduce the possibility that changes in the child's behaviour over time were simply an artefact of changes in the number of requests made by the mother.

#### ***(I) Spontaneous physical contact***

This category covered instances in which the child spontaneously initiated physical contact, as opposed to physical contact which the mother had initiated or asked the child to make. It was subcategorised as being either neutral-positive or negative. Negative physical contact covered behaviours in which the child was aggressive and included biting, scratching, and hitting. Neutral/positive contact was for any non-aggressive contact.

#### ***(II) Stereotypical movement***

Instances in which the child made any simple repetitive movement such as hand flapping, flicking fingers in front of their face, and spinning objects with their hand were coded as stereotypical movement.

### ***(III) Spontaneous eye to-face-contact***

This was when the child spontaneously looked at the mother's face. Occasions where the child looked at the mother's face in response to a request from the mother to do so were not included. Eye-to-face-contact was coded as opposed to eye-to-eye-contact because for many of the categories there was a need to film the whole of the mother and child and not just their faces. This inevitably resulted in a lack of close-up shots which made it difficult to accurately judge whether or not eye-to-eye contact had been achieved.

### ***(IV) Laughter***

Frequency and duration of laughter were coded, as in the maternal behaviour coding.

### ***(V) Spontaneous vocalisations***

This category covered all language-like vocalisations which the child spontaneously made, as opposed to those elicited by the mother asking a question or instructing the child to say something. They were subcategorised as being one of three types – word approximations, proper words, and echolalia. Word approximations included babbling and part-words. Proper words were coded when the child said whole words, even if these were not appropriate to context. Echolalia was coded when the adult said something and the child immediately repeated it back in a similar tone, or when the child used delayed echolalia. Squeals of delight, crying, and whining were not included in the category of vocalisations, as these are not language-like.

#### **7.4.3 Mother versus child task selection**

Task selection was coded when a new task was either suggested or begun. A task did not have to be followed through – tasks which were suggested but not followed through were also included. To avoid coding momentary distractions as new tasks, anything which the child or mother did had to last more than 10 seconds to be classified as a task. The task did not have to involve objects, nor did it have to be a 'typical task'. For example stereotypical movement by the child was coded as a new task if this seemed to be the main focus of the child's attention, and lasted for longer than 10 seconds. In sum, a new task was coded when the activity selected appeared to be something new and not simply an expansion of the previous task. When it was impossible to tell who had selected the task, e.g. if the child had been out of camera shot when the task was begun, the code 'unclassified' was used.

#### **7.4.4 Reliability of analysis**

For each behavioural category, 10% of the 42 videotapes collected were scored by a second observer who was blind to the purpose of the study. Overall 10 videotaped sessions were used for inter-rater reliability, the minimum required to represent all

children and all behavioural categories. Reliability measures were obtained for each behavioural category (table 7.5). There was judged to be agreement that a behaviour had occurred if the onset time coded by the second observer occurred within a 5 second window of the event coded by first observer. In terms of duration, there was agreement if the offset time was also within a 5 second window. In all cases the agreement percentage is reported.

The average percentage agreement was 78%. This is a respectable level, particularly given that continuous sampling is likely to have a lower level of agreement than time sampling methods of analysis (Martin & Bateson, 1993). The agreement level of 65% for eye-to-face-contact is somewhat concerning, although not unpredictable given that filming could not be limited to close-ups of the mother and child's faces without compromising data collected on the other behavioural categories which required full-length filming. Although findings relating to eye-to-face-contact have therefore been included in the analysis, they must be considered cautiously.

Table 7.5: Inter-observer reliability

Behavioural category		% agreement frequency	% agreement duration*
Mother's	imitation	76%	75%
	requests	80%	-
	non Son-Rise techniques	91%	-
	praise	80%	-
	laughter	82%	82%
Child's	physical contact	72%	70%
	stereotypical behaviour	82%	82%
	eye to face contact	65%	65%
	laughter	77%	77%
	vocalisations	77%	77%
Task selection		71%	-

\* Where an appropriate measure

Subcategories of behaviours were also analysed for inter-observer reliability (table 7.6). Where there was agreement that a behaviour had taken place the second observer was asked to code the subcategories of that behaviour. Cohen's kappa was used to correct for chance agreements (Bakeman & Gottman, 1986). The kappa scores for all these behaviours are extremely high, most probably due to the fact that only cases where there was initial agreement that the behavioural category had taken place were included; those excluded may have had more ambiguous subcategories. Although the kappa score for the child's vocalisations subcategories was somewhat lower than the other subcategories this may have been related to the fact that the second observer was much less familiar with the videotaped material than the first observer and had not spent time with the



children participating in the study. The first observer was therefore in a much better position to make judgements on when the children were using echolalia as opposed to proper words and also, with the benefit of having watched the videotapes many more times, was also more able to distinguish proper words from word approximations.

Table 7.6: Inter-observer reliability - subcategories

Behavioural subcategory	Kappa score
Type of request: instruction/question/indirect request	0.93
Type of non Son-Rise technique: criticism/refusing child's request/introducing task when child occupied/ physical manipulation/persisting despite child's objection	1
Praise given for child's: own action/compliance with request/refusal to comply with request	0.93
Type of physical contact: neutral-positive/negative	0.98
Type of child's vocalisation: word approximation/proper word/echolalia	0.76
Task selected by: mother/child/unclassified	0.95

At the end of video analysis one videotape, which contained examples of all eleven behavioural categories, was re-coded in full by the first observer, to provide information on intra-observer reliability, that is how consistently the behavioural definitions had been applied over time by the researcher herself (Martin & Bateson, 1993). There was 82% agreement between codings of categories and 80% agreement if subcategories were also considered. This suggests that observer drift was at an acceptable level during coding.

## 7.5 Video analysis findings

### 7.5.1 Intervention fidelity

Initial intervention fidelity in session 1 was examined in terms of non-SRP techniques, task selection, and imitation. Due to restrictions of space, and previously discussed difficulties in identifying required frequency of technique use to satisfy conditions of intervention fidelity, the other three maternal behaviour categories were not analysed in relation to initial intervention fidelity.

#### *Non-SRP techniques*

In 4 of the 6 pairs there were no occurrences of non-SRP techniques during the first session, indicating a high degree of intervention fidelity on initial implementation of the Program. In pair I non-SRP techniques were used on 10 occasions and in pair K on 4

occasions. In the case of Mrs. I use of these techniques related to the fact that some modifications had yet to be made to the playroom at the time of session 1. Frosted plexiglass had still to be fitted to the window and Ian was distracted by children playing outside. The two-way mirror was not fitted to the door at that stage and Ian sometimes threw toys through the hole in the door where the mirror was to go. To distract Ian away from his activities at the door and the window, Mrs. I introduced new tasks and led Ian to them to encourage him to become involved in interacting with her again, a technique which, although not part of the SRP, was ultimately successful on all occasions. In the case of Mrs. K, non-SRP techniques were used to encourage Kevin to stop his stereotypical behaviour and begin painting instead. They were also used to try and prevent Kevin from leaving the room, as at that stage Kevin had access to the key for the door, which was not the case in later sessions.

*Task selection*

As table 7.7 shows, for 5 of the 6 pairs the proportion of tasks selected by the child was far higher than the proportion selected by the mother, again suggesting a high degree of intervention fidelity. Family I was the only one in which the mother selected a higher proportion of tasks than the child – 62%. This was partly because Mrs. I was introducing tasks to distract Ian away from the door and the window, as described above.

Table 7.7: Percentage of tasks selected by mother and child in session 1.

Pair	% tasks selected by child	% tasks selected by mother
G	100	0
H	93	7
I	38	62
J	87	13
K	74	26
L	92	8

*Imitation*

All of the mothers used imitation during session 1, suggesting that there was at least some degree of intervention fidelity (table 7.8). The number of times imitation was used varied greatly from 6 occasions to 66 with total duration of imitation ranging from 22 seconds to 3 minutes 36 seconds. As previously noted it is impossible to state the amount of imitation which would reflect an acceptable level of intervention fidelity, although total durations of less than a minute do seem rather low, given that imitation is one of the main features of the SRP. However, it is important to consider the mother’s imitation in relation to the child’s behaviour. For example, in the pairs with the shortest durations of imitation, pairs I, J and L, the children displayed no stereotypical behaviour and only one instance of echolalia between them. This undoubtedly limited the mothers’ opportunities

for imitation. Further analysis of pair H reveals a similar situation. Here imitation was used for a total of 1 min 14 seconds. As this occupied only 6% of the total session it initially appears to be a rather low level of imitation. However, although the total duration was relatively short, imitation was used on 66 occasions, the majority of which were imitations of Harry's word approximations. Harry used spontaneous word approximations on 61 occasions, stereotypical behaviour on 5 occasions, and produced no instances of echolalia. Thus while imitation may have taken up a relatively low proportion of the session its use was incredibly high in terms of the proportion of Harry's preverbal and stereotypical behaviour which was imitated.

Table 7.8: Imitation in session 1

Mother	Frequency imitation	Duration imitation	% of session imitation used
G	12	3 min 3 sec	15
H	66	1 min 14 sec	6
I	7	0 min 42 sec	4
J	13	0 min 22 sec	2
K	50	3 min 36 sec	18
L	6	1 min 2 sec	5

***Summary of initial intervention fidelity***

To the extent that intervention fidelity could be measured, it seemed to be reasonably high in at least 5 of the 6 pairs. In 4 pairs there were no instances of non-SRP techniques and in 5 of the pairs the proportion of tasks selected by the child was far higher than the proportion selected by the mother. There were instances of imitation in all 6 pairs, and although the duration seemed relatively short in several cases, this may have been related to the fact that the children in these pairs displayed no stereotypical behaviour and minimal echolalia. As further analysis of pair H showed, duration of imitation as a measure of intervention fidelity may be deceptive unless considered alongside the frequency and duration of the child's verbal and stereotypical behaviour.

**7.5.2 Relation of intervention fidelity to timing of initial training**

If initial intervention fidelity was related to time since training, it would be expected that the longer the time between initial training and implementation of the intervention the lower intervention fidelity – as indicated by a higher use of non-SRP techniques, a lower proportion of tasks selected by the child, and a lower use of imitation.

In terms of non-SRP techniques there did not seem to be a relation between intervention fidelity and time since training (table 7.9). Pair I, which had the largest number of non-SRP techniques in session 1 implemented intervention only 3 months after training.

a shorter time than three of the other pairs, who showed a lesser number of Non-SRP techniques.

Table 7.9: Relation between time between initial training and non-SRP technique use

Mother	Time since training	Frequency of non-SRP techniques in session 1
H	<1 month	0
G	< 1 month	0
I	3 months	10
J	6 months	0
K	13 months	4
L	13 months	0

In figures 7.1 and 7.2, families were plotted along the x-axis in ascending order of time between training and intervention implementation. This was compared against % of tasks selected by the child in session 1 (figure 7.1) and duration of imitation (figure 7.2). No obvious relationship between time since training and either proportion of child task selection or duration of maternal imitation is evident.

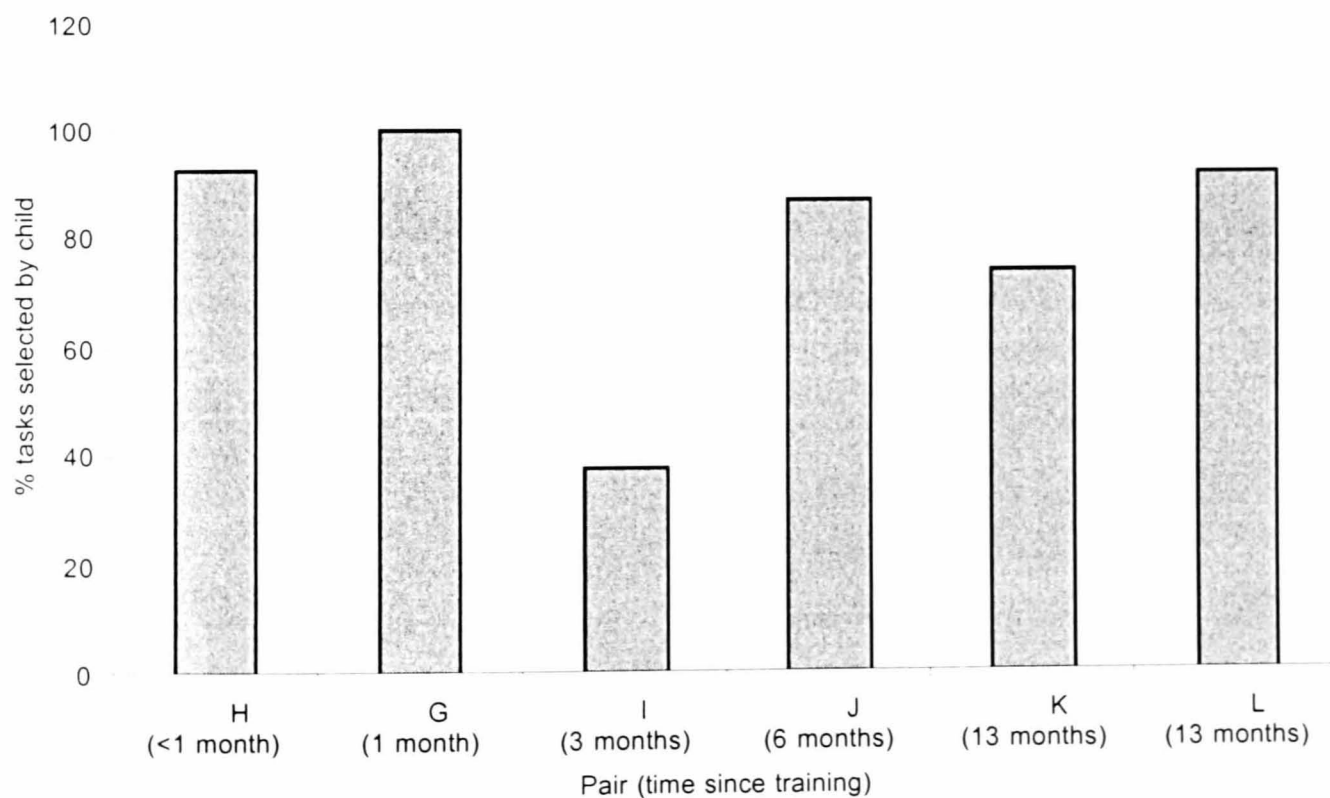


Figure 7.1: Relation between time since training and child's task selection

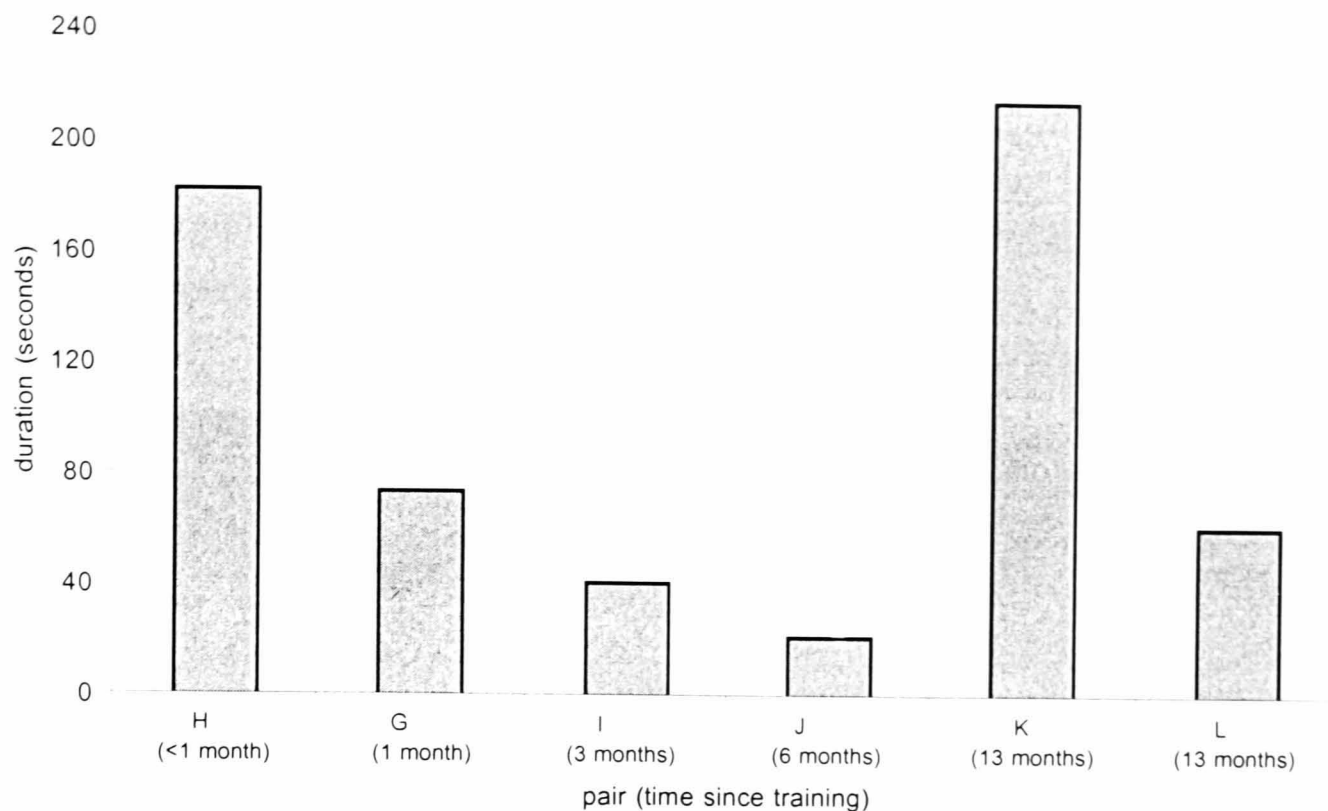


Figure 7.2: Relation between time since training and mother's use of imitation

### 7.5.3 Therapist drift

If therapist drift did occur in the SRP there would be an increase over time in frequency of requests, use of directive types of request, adult task selection and non-SRP techniques and a decrease in maternal imitation, child task selection, praise, and laughter. For mothers receiving ongoing training any increase in adult-led techniques and/or a decrease in child-led techniques, praise and laughter might be expected only until training occurred.

#### *Requests*

Figure 7.3 shows variation in the number of original requests made by each mother over time and figure 7.4 shows the number of original plus repeated requests. From both graphs a pattern suggestive of therapist drift seems evident in 3 of the 6 pairs. Mrs. I received no ongoing training and the number of requests which she made increased steadily over time from session 1 to session 5, continuing to increase when she switched to the Lovaas approach in sessions 6 and 7. This trend is more evident in figure 7.3 than in figure 7.4. Both figures 7.3 and 7.4 indicate a pattern suggestive of therapist drift for Mrs. K in relation to both Kevin and Laura. With both children there was an increase in number of requests between sessions 1 and 2. A visit to the Option Institute with Kevin between sessions 2 and 3 corresponded with a decrease in requesting in both pair K and pair L. Requesting stayed low for several sessions before increasing again in sessions 6 and 7. Although Mrs. K felt that the training that she received after session 2 had the

biggest impact on her use of the SRP, her visit to the Option Institute with Laura, after session 4, also corresponded with a slight decrease in her requesting.

In addition to these 3 pairs, an interesting pattern is shown in pair H. Mrs. H showed a steady level of requesting throughout the study until an increase in session 7 (ongoing training occurring between sessions 6 and 7). This could be suggestive of therapist drift towards the end of the study, but if so this was both late in onset and contrary to the normal direction of the effects of ongoing training.

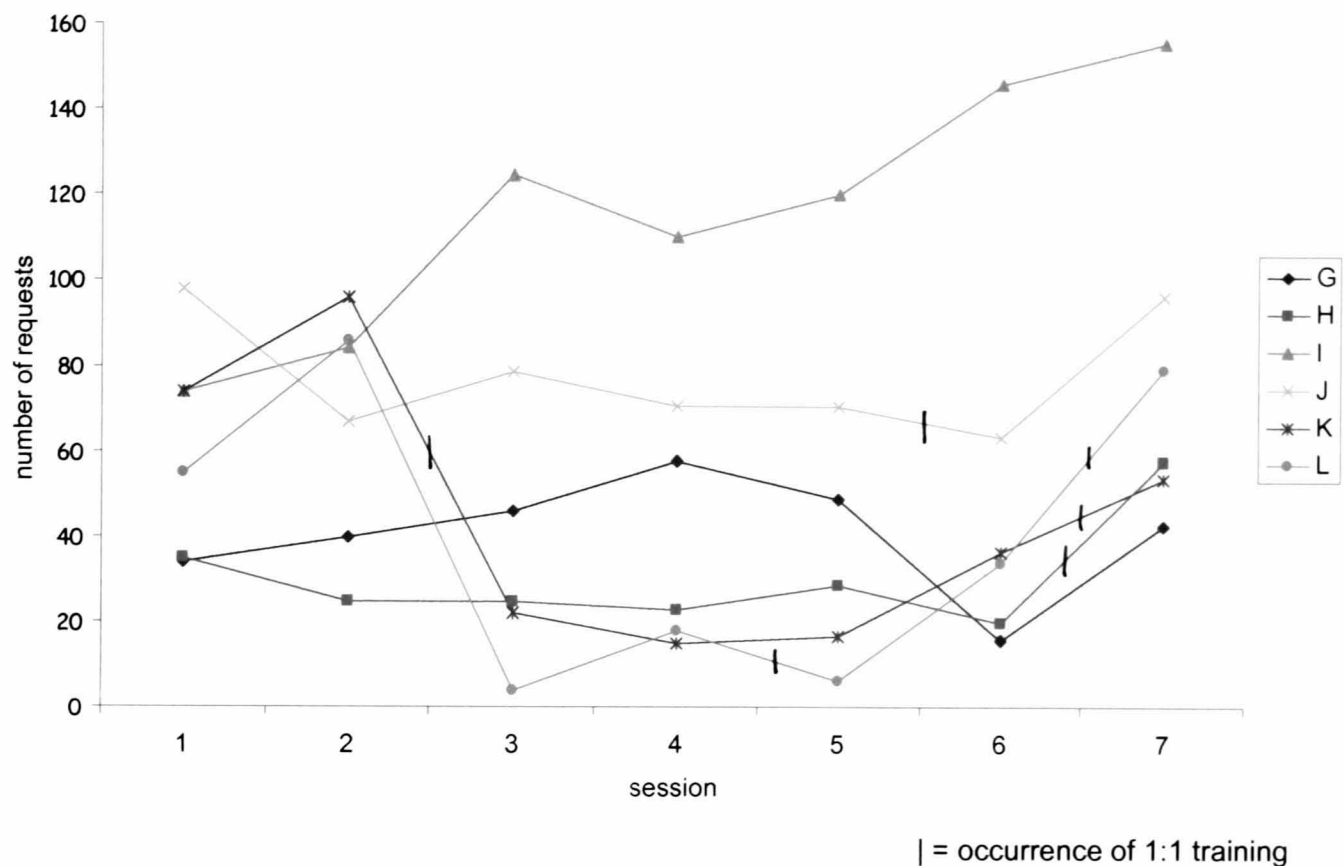


Figure 7.3: Variation in number of original requests made over time

As well as the changes over time it is also interesting to note the enormous variation in the number of requests made per session, with large differences both between pairs and within pairs over the course of the study. Within the 20 minute Son-Rise sessions which were subjected to analysis the number of original requests varied from 4 (pair L, session 3) to 125 (pair I session 3), although the latter is still lower than the number of requests in pair I's Lovaas sessions (147 in session 6, 157 in session 7).

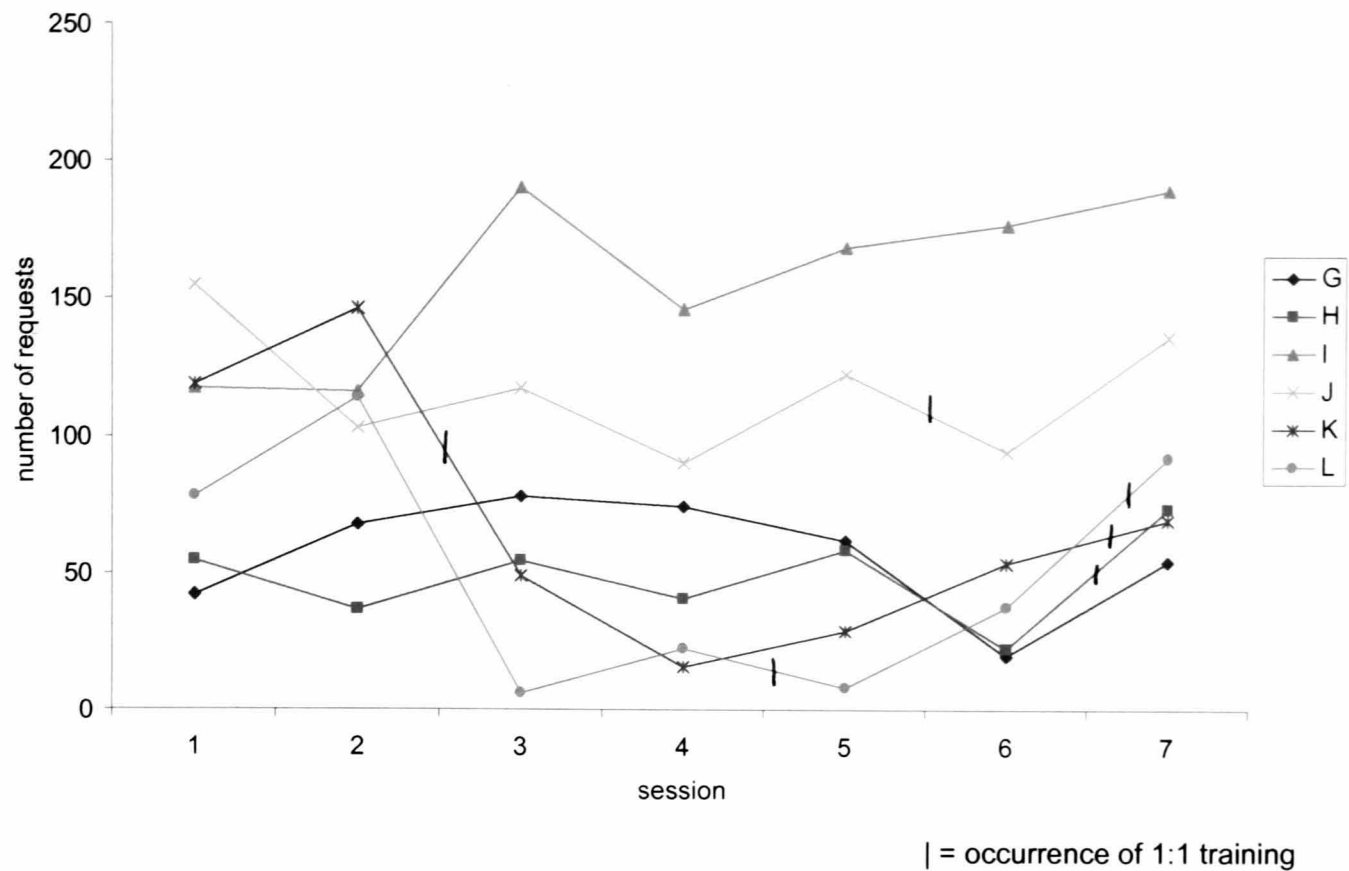
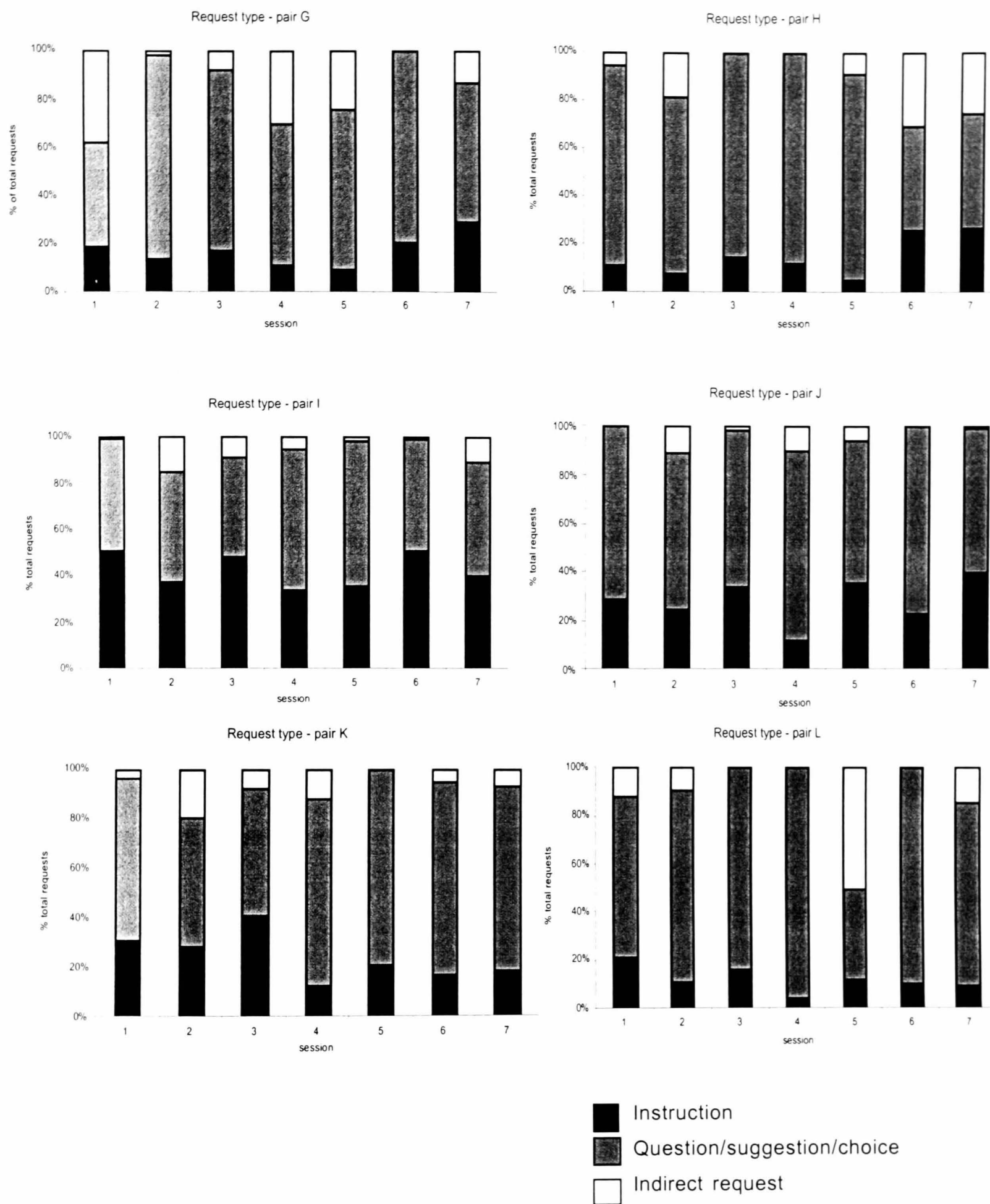


Figure 7.4: Variation in number of original + repeated requests made over time

### *Type of requests*

If therapist drift occurred it would be expected that there would be an increase over time in the proportion of requests that were instructions and an decrease in the proportion that were less directive, i.e. questions, suggestions, choices and indirect requests.

Figures 7.5 – 7.10 show the variation over time in the type of requests used by the mothers. While the majority of pairs had a sufficiently high number of total requests (including repeated requests) to warrant conversion to percentages, pairs K and L had a low number of requests in sessions 3 – 5, with total number of requests lower than 10 in some cases. While it is usually unwise to convert such small figures to percentages in this case it does assist in illustrating the trends over time.



Figures 7.5 - 7.10: Variation in type of request used over time: Pairs G - L



Mrs. G, who received no ongoing training during the time of the study, did not show an increased use of direct instructions over time, and hence no evidence of therapist drift. There was though great variation between sessions in the proportion of requests that were indirect. This seemed to be related to the particular activities the pair were engaged in during the session, e.g. in sessions where the pair did lots of singing there was a high proportion of indirect requests because Mrs. G left blanks for George to fill in.

Mrs. H, who received training after session 6, showed an increase in use of instructions in sessions 6 and 7. However, this, was balanced by an increased use of indirect requests.

Mrs. I had a pattern which, although not indicative of therapist drift, does show a high use of instructions throughout the study, with little difference between sessions 6 and 7 (the Lovaas approach) and her earlier Son-Rise sessions.

Pairs J, K and L do not show an increase in use of instructions over time, hence no evidence of therapist drift. Pair L showed an increase in indirect requesting following training between sessions 4 and 5, but as the total number of requests in session 5 was so small this is unlikely to be of any significance.

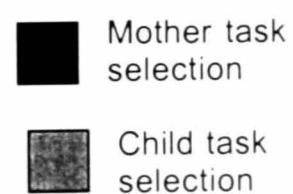
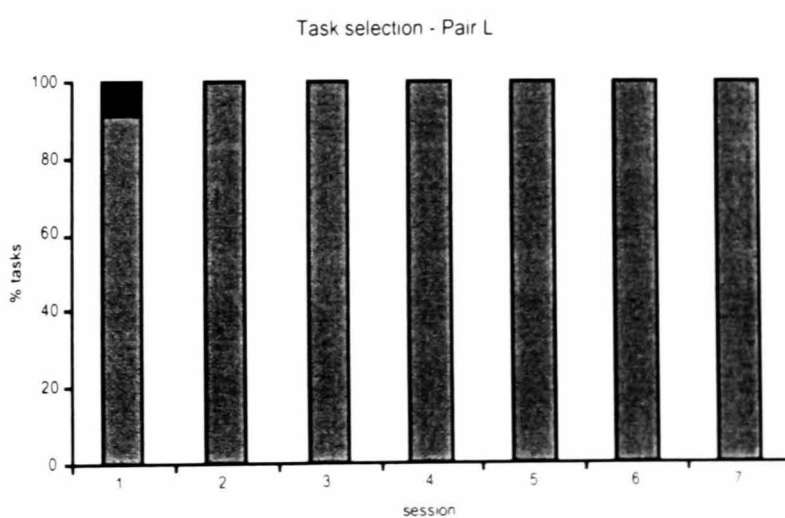
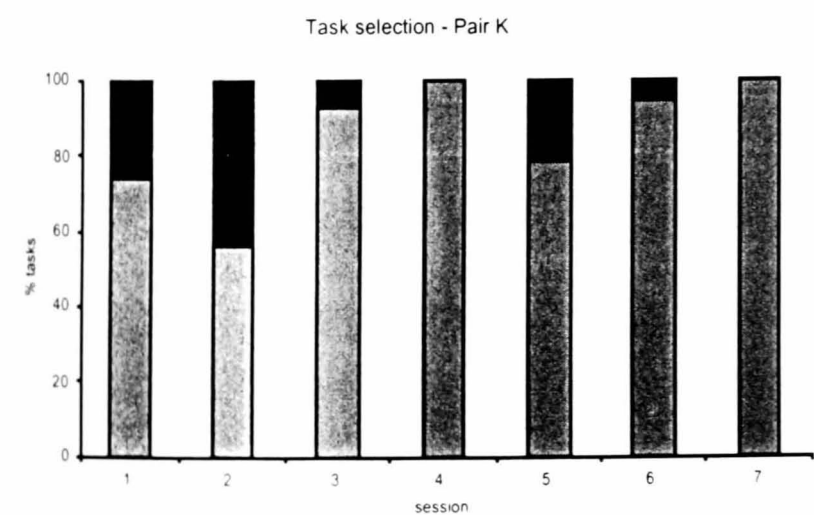
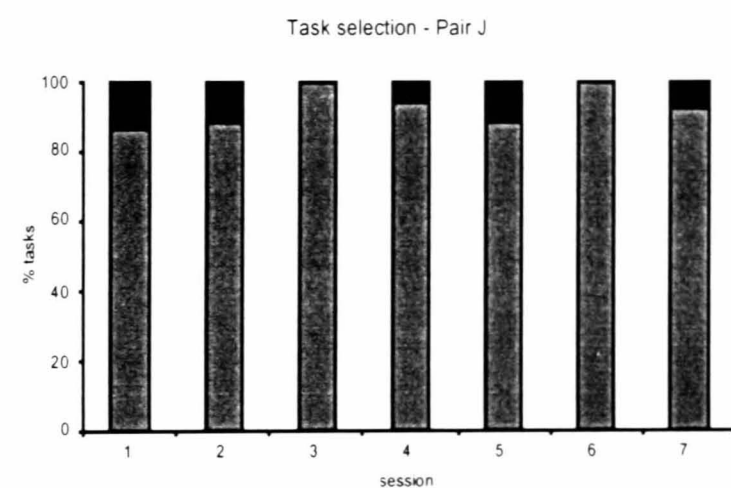
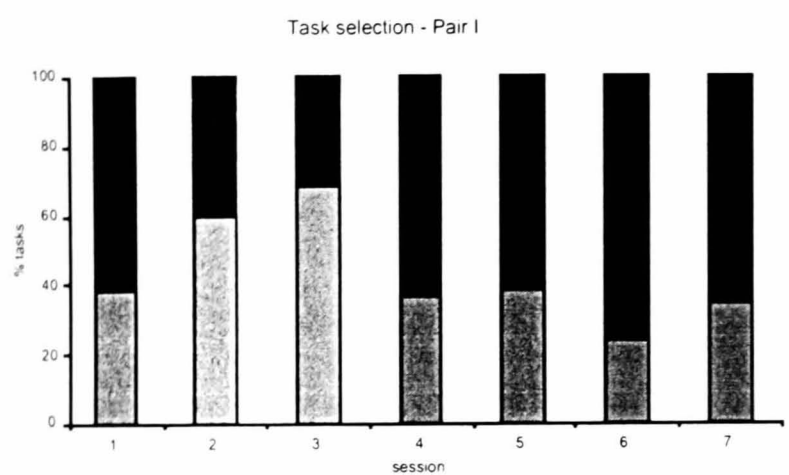
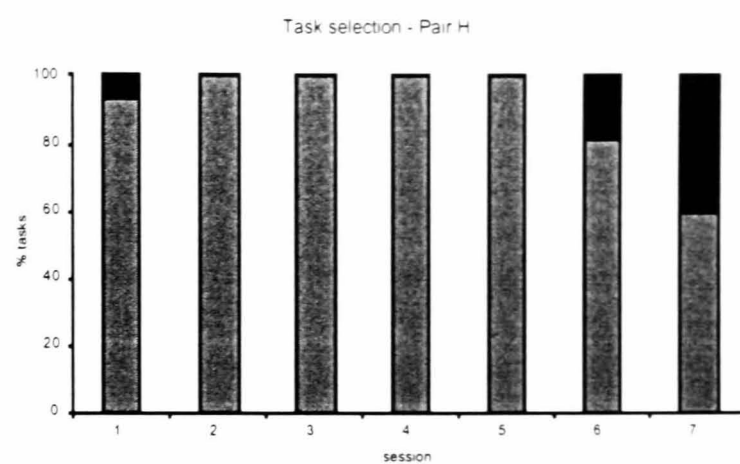
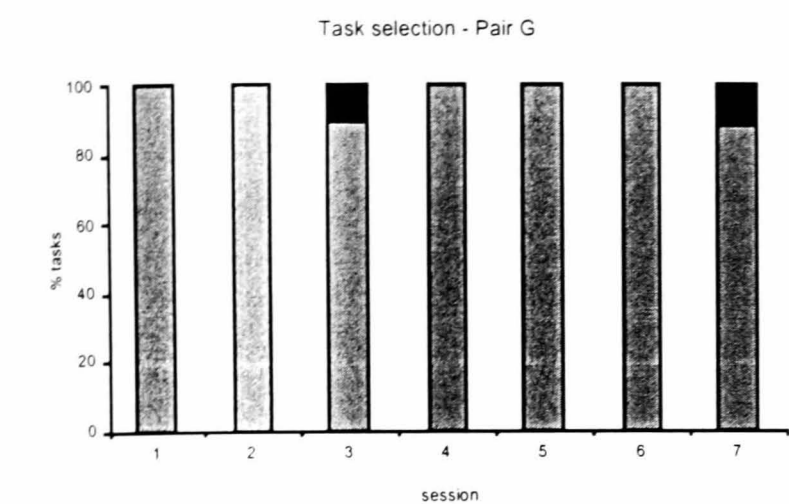
### *Task selection*

If therapist drift did occur there would be an expected increase over time in the proportion of tasks selected by the mother and a decrease in the proportion selected by the child. In the case of mothers who received ongoing training it would be expected that task selection by the mother would increase until training occurred and then decrease. Figures 7.11 – 7.16 show the proportion of tasks selected by the mother and child in each pair (instances where it could not be established who selected the task have been omitted). The total number of tasks selected by the mother and child in any session varied from 1 to 27 (including those that were suggested but did not go ahead). Again, while the conversion to percentages makes trends more apparent, conclusions must be drawn cautiously and patterns suggestive of therapist drift must also be considered in terms of changes in absolute number of tasks engaged in during the session.

From figures 7.11 – 7.16, there appears to be little evidence of therapist drift. In pairs G, H, J, and L the child chose the majority of the tasks in every session, with no increase over time in the proportion chosen by the mother. Pairs G and L in particular have an extremely low level of task selection by the mother. Indeed all pairs, with the exception of pair I, show a much lower level of adult task selection throughout the study than the 52% found by Jordan and Powell (1996).

Pair H did show a slight increase in tasks selection by the mother in sessions 6 and 7, with two tasks selected by her in session 6 and four in session 7 compared to none in the previous four sessions. Combined with the increase in requesting shown in session 7, this may be suggestive of therapist drift towards the end of the study.

Pair K showed a pattern which was somewhat suggestive of therapist drift in that the proportion of tasks selected by the mother increased from session 1 to session 2, at which time Mrs. K received further training. The proportion of tasks selected by her thereafter remained low for the remainder of the study. In terms of number of tasks selected by Mrs. K, 7 were selected in session 1 and 10 in session 2. This dropped to either 1 or 0 for the remaining sessions, with the exception of session 5 in which she selected 3 tasks. This increase in session 5, may have been unrelated to therapist drift; Kevin was unsettled and had a much higher level of aggressive behaviour during this session than at any other time in the study and Mrs. K seemed to be introducing tasks because he was not choosing activities as he usually would.



Figures 7.11- 7.16: Task selection

Pair I showed a pattern which, although not suggestive of therapist drift, does show a very high proportion of tasks selected by the mother throughout the study, with more tasks selected by her than the child in all sessions except for 2 and 3. As with request type there is little difference between sessions 6 and 7 (Lovaas approach) and earlier Son-Rise sessions. If tasks which were suggested but not actually carried out are removed from the graph (figure 7.17), the pattern is more suggestive of therapist drift, with a fairly steady increase in the proportion of tasks selected by the mother over time. In the first session 3 tasks were carried out which had been selected by Mrs. I, rising to 16 by session 7.

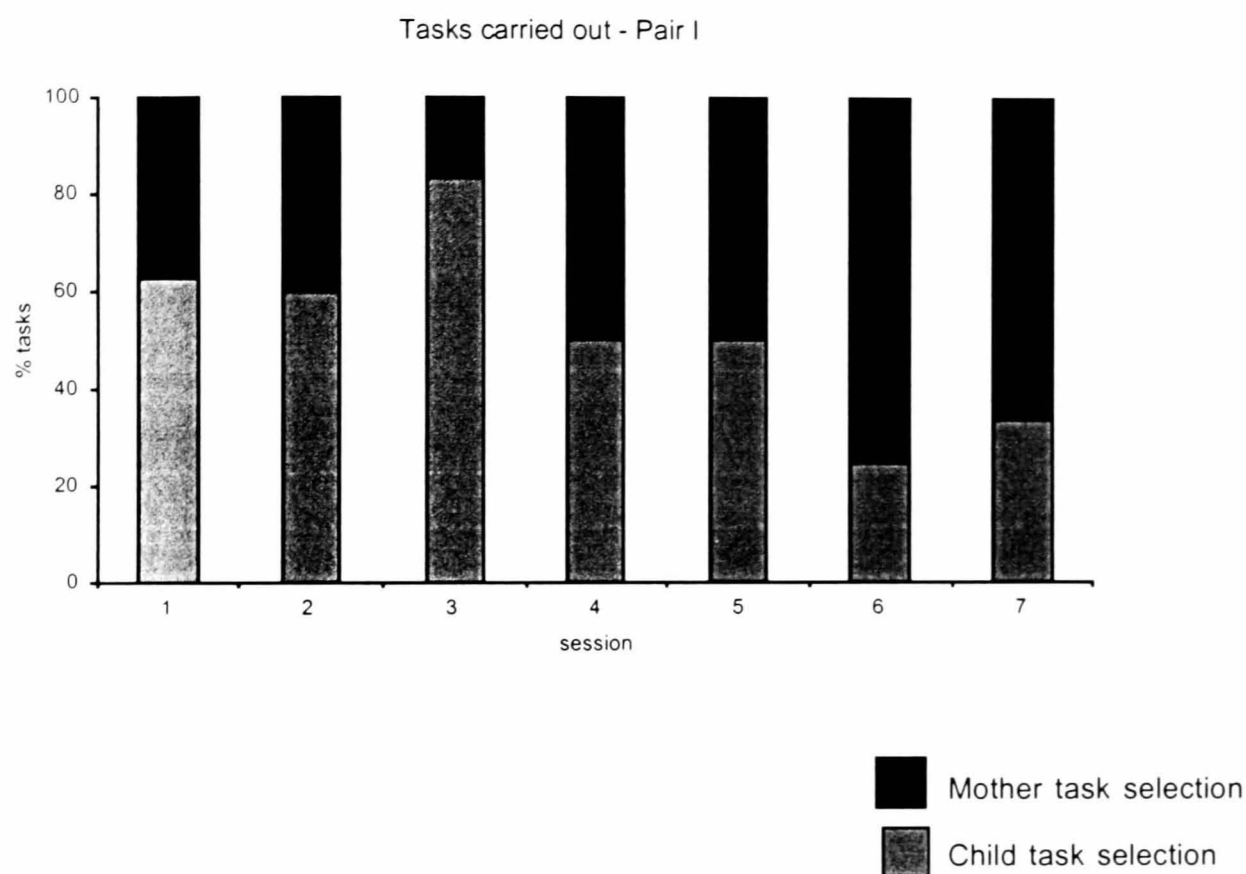


Figure 7.17: Pair I - tasks carried out

### *Non-SRP techniques*

If therapist drift occurred it would be expected that the frequency of non-SRP techniques would increase over time, or until such time that ongoing training occurred. As table 7.10 shows, occurrence of non-SRP techniques was in fact minimal throughout for most pairs. Where non-SRP techniques were used this was mainly to distract the child from doing something disruptive, such as throwing toys around the room, or something which in non-SRP terms might be considered unproductive stereotypical behaviour.

Table 7.10: Number of non-SRP techniques used in each session

Pair	Session						
	1	2	3	4	5	6	7
G	0	0	0	0	0	0	0
H	0	0	0	0	0	0	0
I	10	4	3	0	5	3	6
J	0	0	0	0	1	0	1
K	4	2	1	0	0	0	0
L	0	0	0	0	0	0	0

Pairs G, H, and L had no instances and pair J only 2 over the year. In pair K there was 4 instances in the first session, which then decreased in the following sessions with none from session 4 onwards. This suggests that Mrs. K became more aware of how to use the Program with Kevin as time went on, and the training that she received following session 2 may have contributed towards this. Although it perhaps seems surprising that she showed some use of non-SRP techniques with Kevin but none with Laura. This may be related to the fact that Mrs. K mainly used such techniques to bring Kevin back to a task once he had become engrossed in stereotypical behaviour and to prevent him from leaving the room in session 1; behaviours which Laura did not display. Pair I had the highest use of non-SRP techniques throughout the year, which combined with a low use of imitation and a high use of requesting suggest the Mrs. I strongly emphasised adult-led techniques.

In terms of the type of non-SRP technique used throughout the study, no parent ever used criticism of their child or denial of their child's requests. Selecting a task while the child was already occupied was the most common non-SRP technique, used 28 times overall. Physical manipulation was used 9 times, usually in combination with the previous technique, and often consisted of leading the child away from an 'unproductive' activity to a new task. Persisting with something after the child had objected was used on 3 occasions.

### *Imitation of child*

If therapist drift did occur, it would be expected that the duration of the session spent imitating the child would decrease over time or in the case of mothers receiving ongoing training, that it would decrease until training occurred and then increase.

Figure 7.18 shows the variation in imitation over time. There is no evidence of therapist drift in pairs G, H, I and J. Pairs I and J have a very low level of imitation throughout, however. As previously mentioned, this may be related to the fact that both Ian and Jill displayed no stereotypical behaviour and virtually no echolalia, perhaps limiting

opportunities for imitation somewhat. While there are changes in the amount of imitation over time, and in pair I's case this does represent something of a downward trend, any fluctuations between sessions amount often only to a 1% change making it unwise to interpret such changes as representing therapist drift.

In pairs K and L there is a pattern more suggestive of therapist drift. In pair K there is a slight decrease in imitation between sessions 1 and 2. Training occurred after session 2 which is followed by an increase in imitation, which then gradually begins to decrease again after session 4. This decrease may have been more linear if it were not for the particularly low level of imitation in session 5, which, as noted above, was an atypical session for the pair. In pair L there was a similar pattern with a very slight decrease in imitation between sessions 1 and 2, followed by an increase after training in session 3, then a decrease again. The pattern is unusual though because of the extremely large increase between sessions 2 and 3 followed by a very sharp decrease between sessions 3 and 4. This can be explained by the fact that Laura spent the majority of her sessions drawing pictures in these sessions. Mrs. K was unsure if this was an interactive activity which she should expand on, or a withdrawn activity which should be imitated. Around the time of session 3 the family were experimenting with imitating the activity. Shortly after this they decided that treating the drawing as an interactive activity would be a more effective strategy. This explains the sharp increase in imitation in session 3. The pattern, although suggesting therapist drift, represents a conscious change of tactics for one session. Pair K are then the only pair with a pattern suggestive of therapist drift.

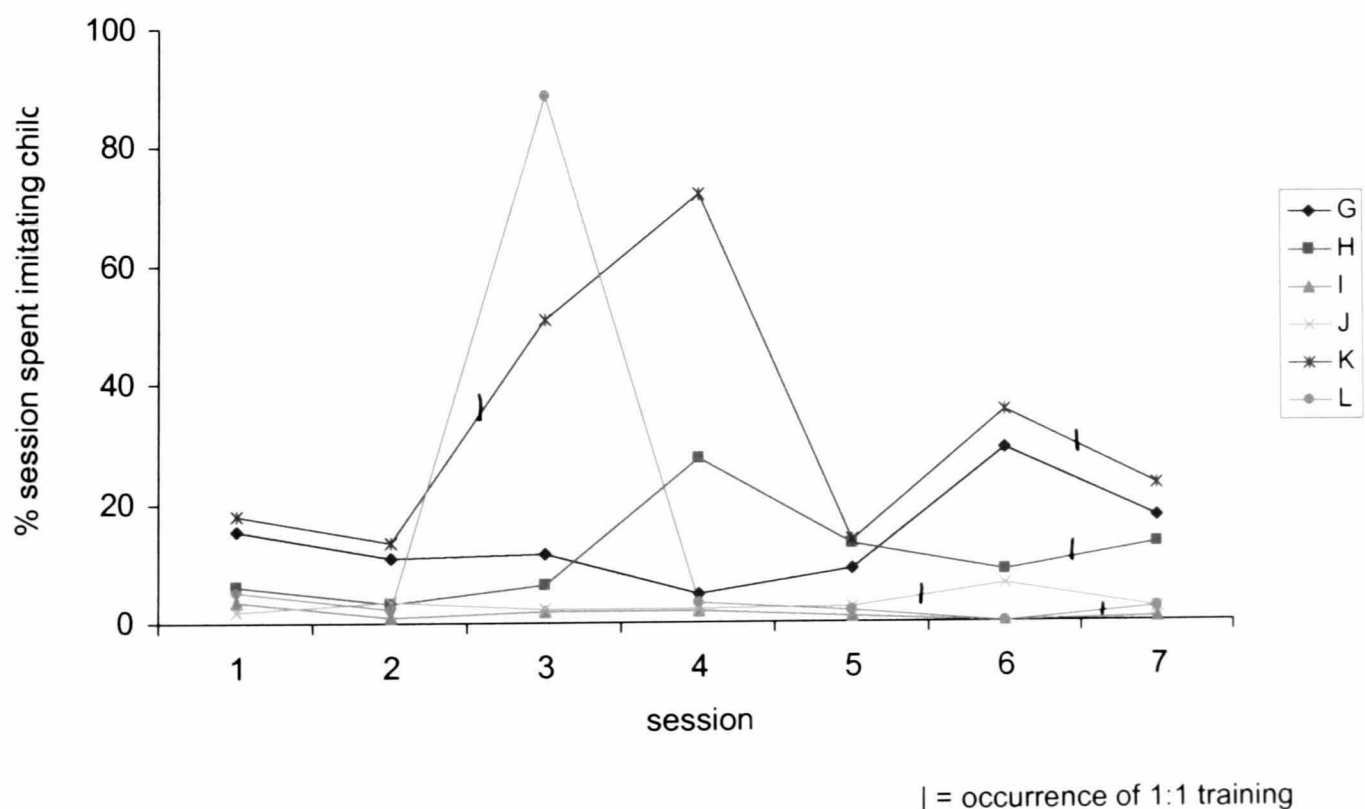


Figure 7.18: Variation in duration of session spent imitating the child

## Praise

If therapist drift did occur it would be expected that the number of times the child was praised each session would decrease over time, or in the case of mothers receiving ongoing training, that it would decrease until such time as training occurred. Praise for the child's own activity in particular may decrease over time, as may praise for refusal to comply with request. In fact this latter type of praise occurred only once across the whole sample during the study, and was therefore dropped from the analysis. This may be related to the fact that children were far more likely simply to make no attempt than to actually refuse to comply with a request.

Figure 7.19 shows the variation in praise (all types) over time. Although there is a greater deal of variation between sessions for all of the pairs none show a pattern that is indicative of therapist drift. If anything, there is some indication of the opposite occurring, with praise increasing rather than decreasing over time; pair I for example show a slight upward trend over time, with a sharp increase in sessions 6 and 7 (Lovaas sessions) and in pair L although there is not a steady upward trend, later sessions (5, 6 and 7) do have a much greater frequency of praising than earlier sessions.

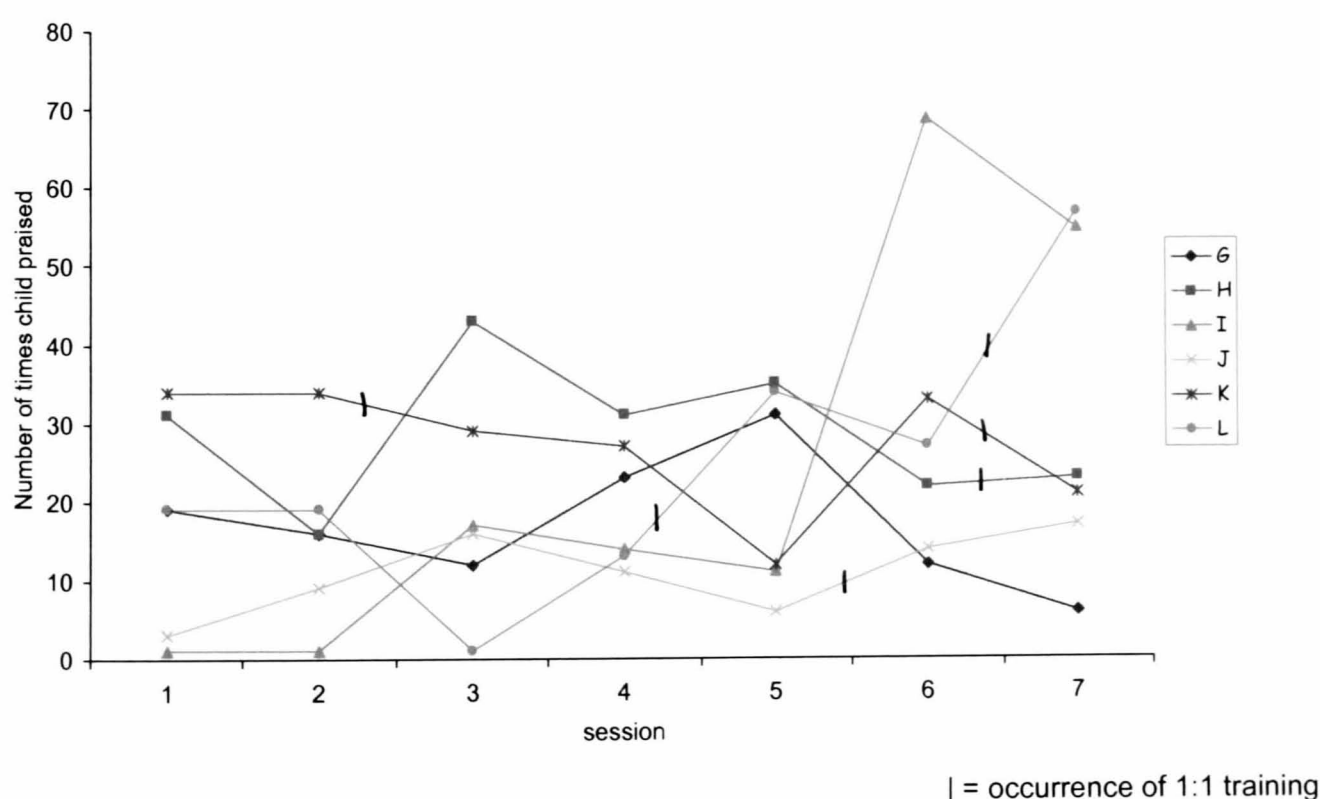


Figure 7.19: Variation in frequency of praise (all types) over sessions

In terms of praise for the child's own action there was again much variation across sessions for all pairs but no evidence of therapist drift (figure 7.20). Pair I had a low level of this type of praise throughout, with Mrs. I tending instead to praise Ian for attempting

to comply with requests which she made. Again pair L had higher levels of praise in later sessions than earlier ones. This increase in later stages may be related to training prior to session 5, which is followed by a particularly sharp increase in praise.

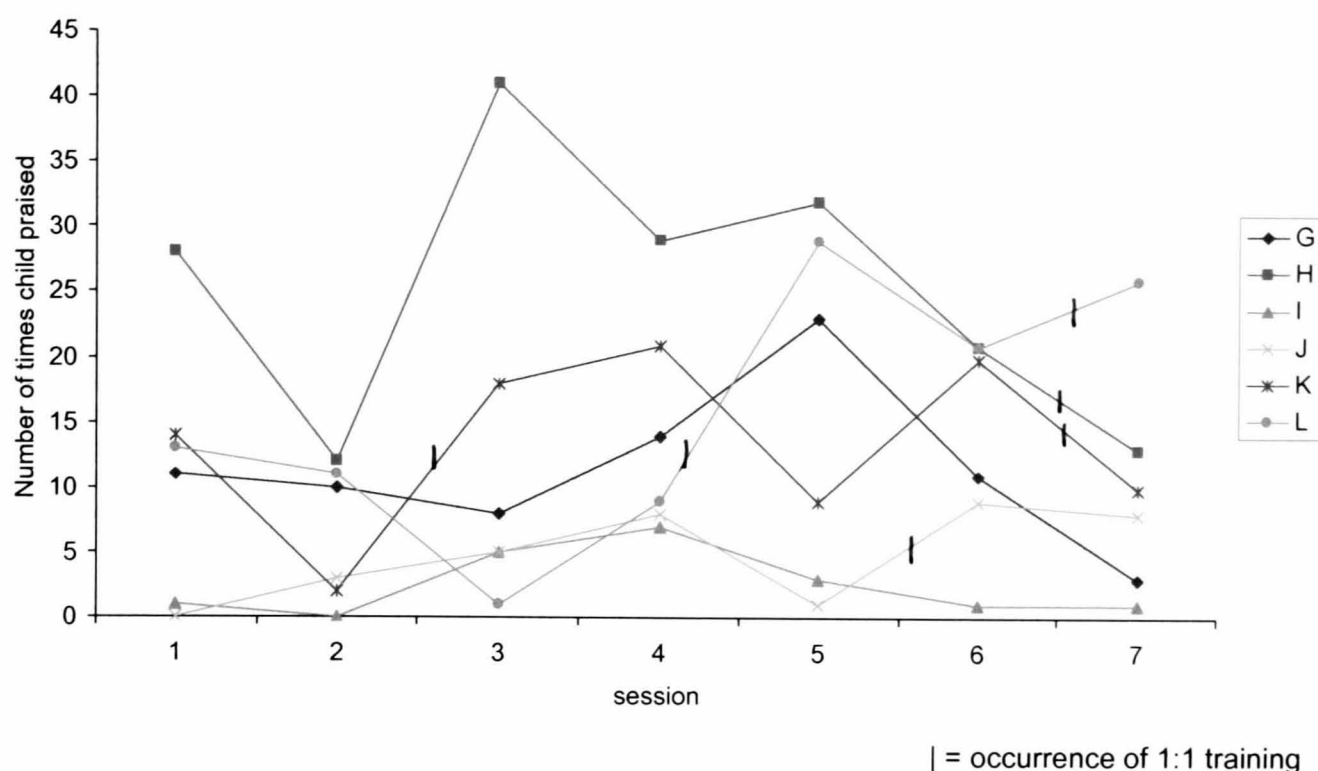


Figure 7.20: Variation in frequency of praise for child's own action over sessions

### ***Mother's laughter***

If therapist drift in the 3Es did occur it might be expected that the amount of time that the mother spent laughing each session would decrease over time, or in the case of mothers receiving ongoing training, that it would decrease until training occurred and then increase. As can be seen in figure 7.21, none of the pairs shows a pattern indicating any decrease in enjoyment of sessions indicative of therapist drift. Mrs. G and Mrs. I received no ongoing training, but do not show a steady decrease in laughter over time. Mrs. H, who received training after session 6, shows great variation in amount of laughter over time, but not a pattern suggestive of therapist drift. Mrs. J showed a fairly steady increase in laughter over time, with a substantial increase following training after session 5. This suggests that the training was effective in this respect, but boosting an already upward trend, rather than remedying therapist drift. Several of the mothers showed an increased level of laughter in session 7 which may have been related in some way to the fact that it was the last filming session, with mothers perhaps keen to demonstrate their continuing enthusiasm for working with their child.



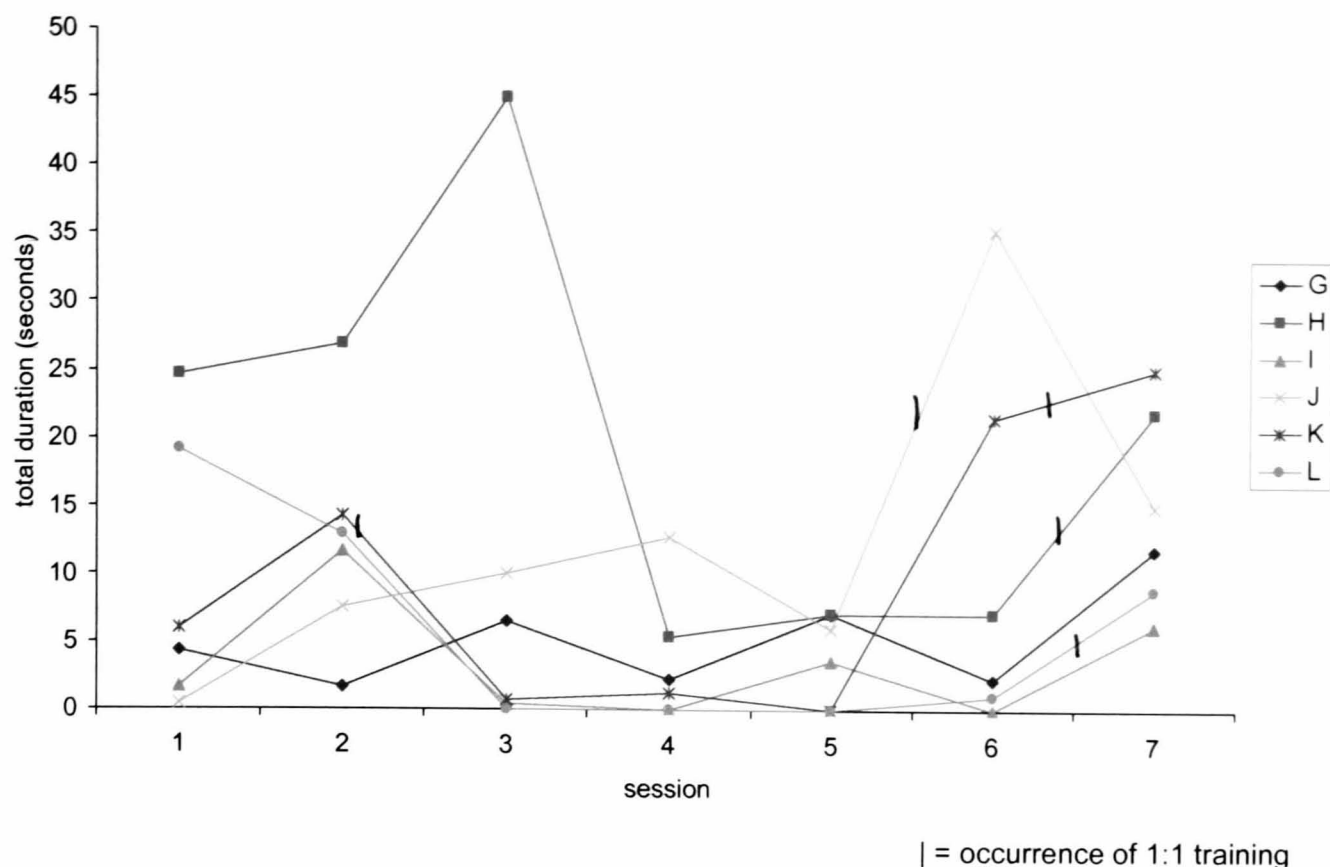


Figure 7.21: Variation in duration of mother's laughter over sessions

### Summary

Overall, patterns which were somewhat suggestive of therapist drift were found in four of the six pairs, although in each pair drift was in relation to a limited range of techniques (table 7.11). The patterns suggestive of therapist drift found in pair H were found only in the final two filming sessions.

Table 7.11: Implementation of Son-Rise techniques suggestive of therapist drift

Pair	Technique						
	requests	type of requests	task selection	non-SRP	imitation	praise	laughter
G							
H	✓*		✓**				
I	✓		✓				
J							
K	✓		✓		✓		
L	✓						

✓ pattern of change suggestive of therapist drift

\* pattern suggestive of therapist drift in final filming session only

\*\* pattern suggestive of therapist drift in final two filming sessions only

Frequency of requesting was the technique where a pattern suggestive of therapist drift was most often found, followed by task selection. In relation to imitation a pattern suggestive of therapist drift was found only in pair K. There was no evidence of therapist drift in relation to any of the other techniques examined. Although levels of non-SRP techniques, praise and laughter varied greatly across sessions, the patterns of fluctuation were in no way suggestive of progressive therapist drift.

In pair I there was a strong emphasis on adult-led techniques in session 1, which remained the case throughout the remainder of the Son-Rise sessions. Frequency of requesting was high as was adult task selection and use of non-SRP techniques, and levels of imitation and praise for the child's own actions were low. This pattern is consistent with Mrs. I's decision to change to Lovaas by session 6.

#### **7.5.4 Relation of child's behaviour to mother's techniques**

In order to explore the relationship between the child's spontaneous behaviour and the mother's use of imitation and requesting, a series of graphs were plotted for each mother-child pair over the 7 filming sessions. Overall, relatively few obvious relationships were found, and those that did exist were often quite weak. For this reason, and due to restrictions of space, only a summary of the findings will be presented here, with selected graphs used to illustrate the main points. The remainder of the graphs can be found in Appendix F.

In all graphs the child's behaviour and the mother's use of imitation are expressed as the percentage of the 20-minute session during which the behaviour was displayed. These relate to the 1<sup>st</sup> y-axis and are displayed as solid lines. The mother's requests are shown in terms of the absolute number per session. This behaviour relates to the 2<sup>nd</sup> y-axis and is displayed as a (single) broken line on each graph. The range of both the primary and the secondary y-axes varies across graphs in order to represent as clearly as possible the relation between the patterns of change in the child's behaviour and the mother's techniques. While the pattern of change is more relevant than the absolute percentage/number of occurrences, care should nonetheless be taken in interpretation of these graphs.

The two child behaviours where consistent relationships were most often found with the mother's techniques were stereotypical behaviour and spontaneous word approximations. However, even in these behaviours, the relationship to the mother's techniques was often fairly weak.

In all pairs where stereotypical behaviour was present (G, H, I and K) there was a positive relationship with maternal imitation as expected. Relationships between stereotypical behaviour and maternal requesting tended to be either absent (H, I and K) or less obvious (G) than the relationship with imitation. Figure 7.22 provides a good example of the type of relationship found. It relates to pair K in which, although there seemed to be some relationship evident, this was not consistent across all sessions; for example there are no obvious links between stereotypical behaviour and maternal imitation in sessions 4 and 7.

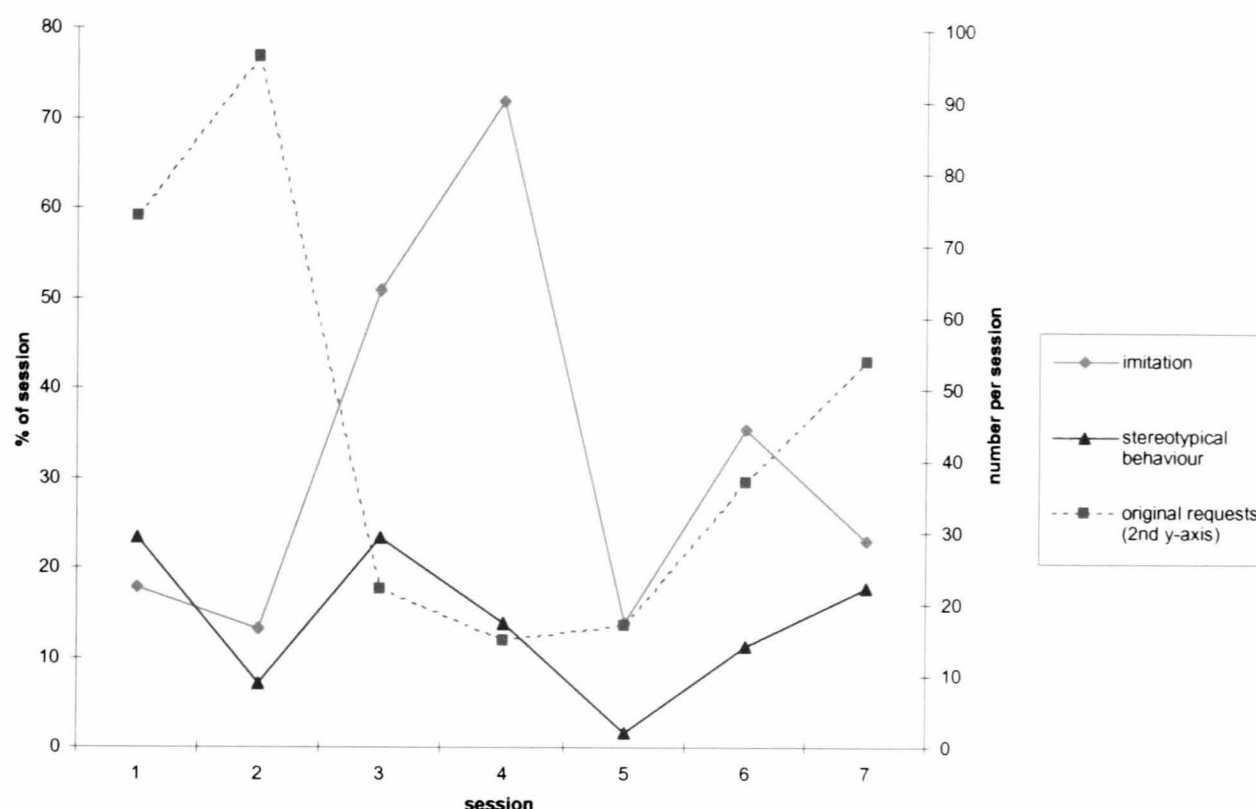


Figure 7.22: Pair K - relation of child's stereotypical behaviour to mother's techniques

With regard to word approximations, all pairs showed a positive relationship between the child's use of these and maternal imitations, with the exception of pair K in which a weak negative relationship was found, and pair L in which no obvious relationship was found. A positive relationship was found both in cases where word approximation represented the child's main method of communication, i.e. pairs H and J, and in pairs where the child had a relatively large vocabulary of proper words, i.e. pairs G and I. In pair H, with the exception of session 7, there appeared to be a very strong relationship between Harry's spontaneous word approximations and Mrs. H's use of imitation (figure 7.23). Throughout the study Harry was at the stage of using a few whole words and a large number of part-words (e.g. 'p' for 'push'). Mrs. H used imitation a great deal as a way of reinforcing his attempts to communicate.

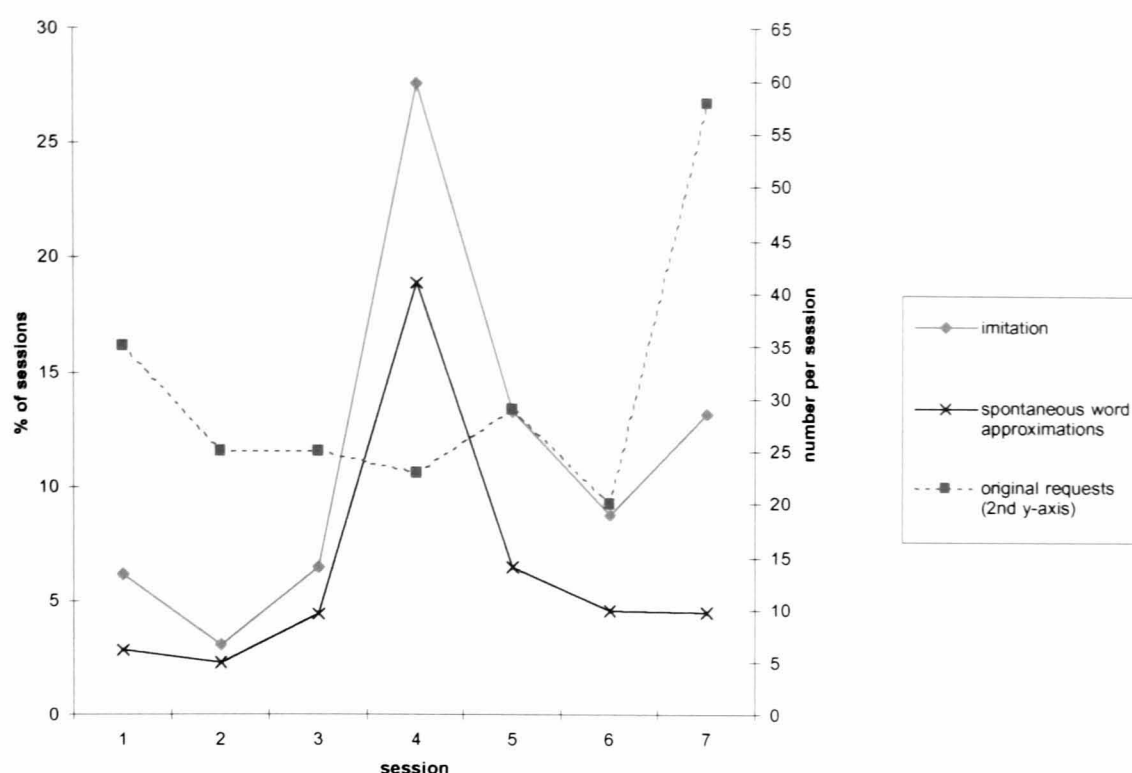


Figure 7.23: Pair H – relation of child's word approximations to mother's techniques

In other mother-child pairs the relationship found between word approximations and imitation was less strong, as illustrated by pair J (figure 7.24). Here, although there does appear to be a positive relationship between word approximations and imitation in most sessions, this is absent in sessions 4 and 5.

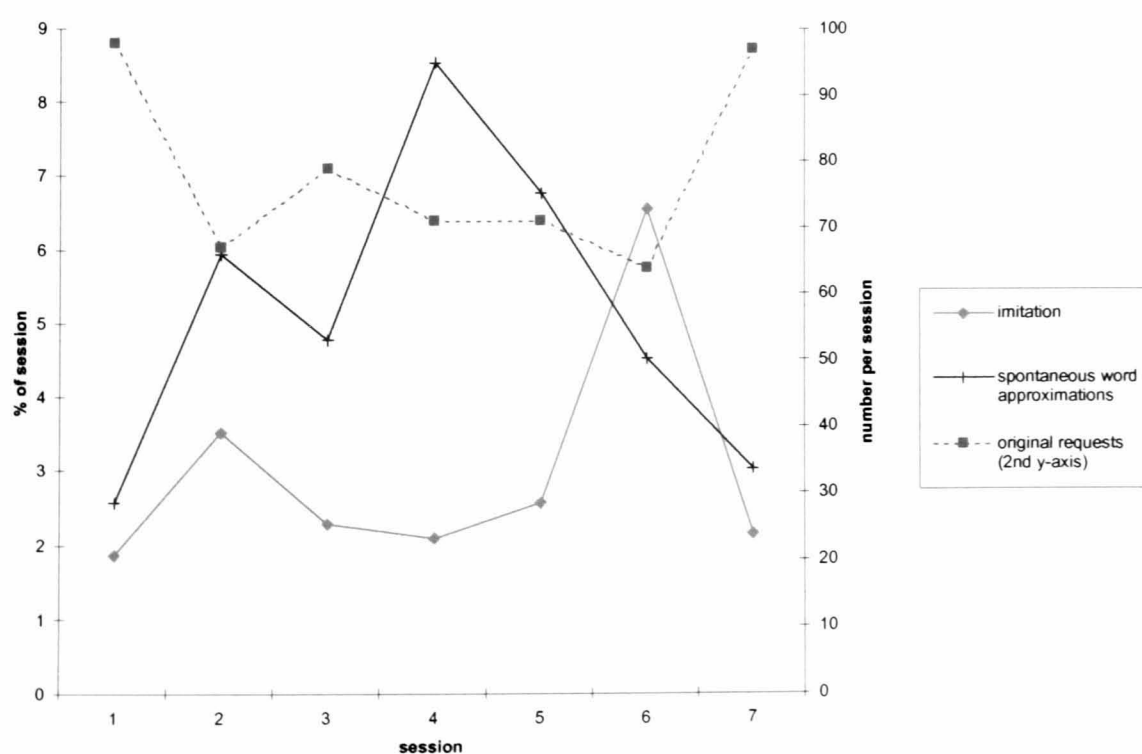


Figure 7.24: Pair J – relation of child's word approximations to mother's techniques

Relationships between maternal and child behaviours were found less often for the other categories of child behaviour, and where relationships did exist there were often conflicting findings. For example in pair H a strong negative relationship was found between physical contact and maternal imitation, whereas in pair J a slight positive relationship was found. In the case of proper words, in pair I there was a weak positive relationship with maternal imitation, whereas in pair G there was a positive relationship with requests. The latter pair therefore showed a relationship in the direction predicted.

Neither echolalia nor eye-to-face contact appeared to relate to the mother's techniques in any of the pairs. The only exception to this was a positive relationship between eye-to-face contact and imitation between sessions 5 and 7 in pair J. This was in the opposite direction from the relationship predicted. The lack of relationships found in relation to eye-to-face contact may have been connected to the difficulty in measuring frequency of eye contact in video analysis.

Exploration of whether patterns suggestive of therapist drift found in the mother's techniques were related to the child's behaviour was attempted. Pairs H, I, K, and L had shown some evidence of therapist drift, but in the majority of cases this did not seem to correspond in any obvious way to changes in the child's behaviour. The only exception to this was in pair K where the changes over time in Mrs. K's imitation were positively related to changes in Kevin's stereotypical behaviour, and changes in her requesting showed a positive relationship with laughter. The relationships were not strong in either case, however (figure 7.25).

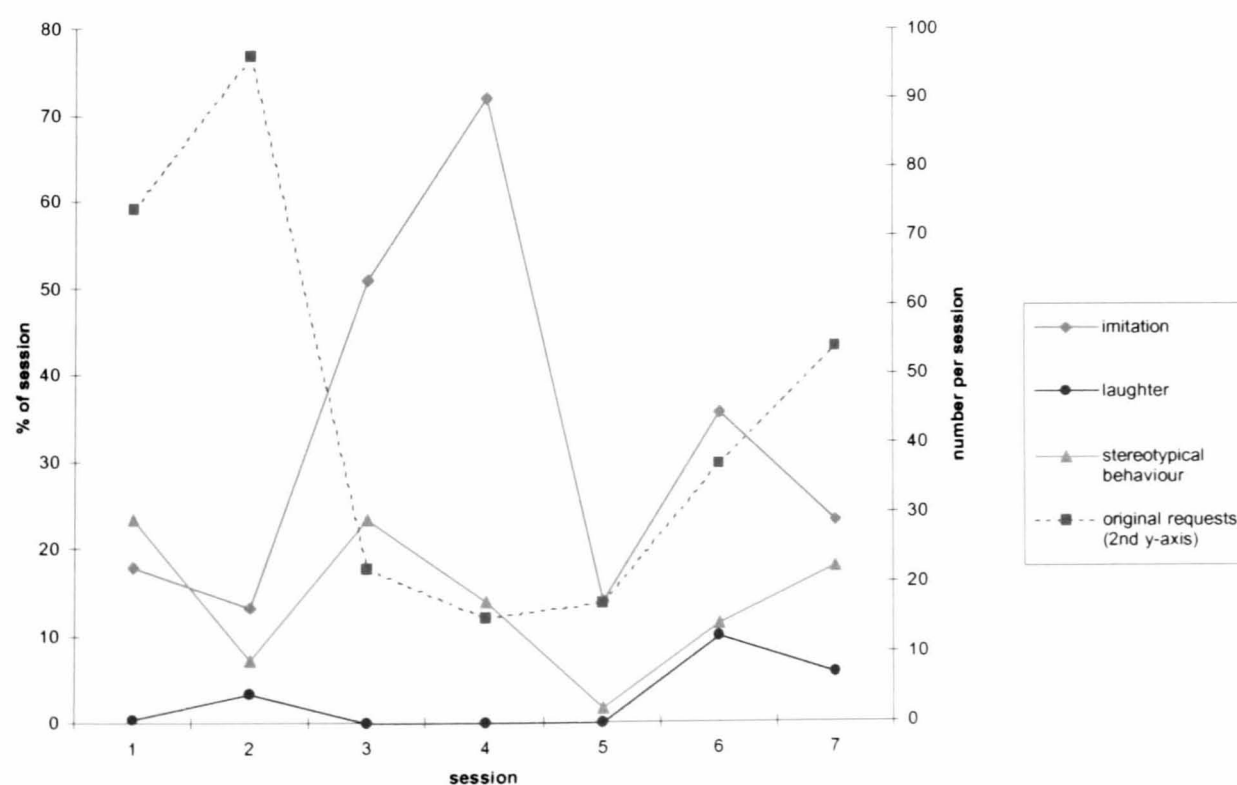


Figure 7.25: Pair K – relation of child's stereotypical behaviour and laughter to mother's techniques

## 7.6 Discussion

This study explored initial intervention fidelity, therapist drift and the relationship of variation in the child's behaviour to variation in the mother's techniques in 6 mother-child pairs involved in the SRP over a one-year period.

Initial intervention fidelity seemed high in four of the six pairs. Imitation was used in all six pairs, but there was some use of non-SRP techniques in two of the pairs in the first filming session, and in one of these pairs, pair I, the proportion of tasks selected by the mother was higher than those selected by the child. This pair continued with a strong emphasis on adult-led techniques through the remainder of the Son-Rise sessions, and changed to the Lovaas approach by session 6. This perhaps indicates that Mrs. I was more used to, or more comfortable with, a structured adult-led approach, as it has been suggested that intervention fidelity can be lower when the intervention is very different from current methods of interaction with which the parent is comfortable (Detrich, 1999; Gage & Wilson, 2000). Again it should be emphasised that while intervention fidelity is desirable in evaluation research, it is not always best for the parent and child.

There appeared to be no obvious relationship between time since initial training and intervention fidelity in session 1. This finding may have been an artefact of the small sample size, and it may be that a relationship would be found if further research was carried out with a larger sample. It may also be the case that no relationship was found because other factors influence initial intervention fidelity more than time since training. These may include the characteristics of the child, the environment in which the intervention is carried out, and the similarity of the intervention to previous methods of interaction (Detrich, 1999).

There was some evidence of change in technique implementation over time which was suggestive of therapist drift in four of the six pairs. While this lends some support to Jordan and Powell's (1996) theory of therapist drift, the fact that it was not found in the majority of the techniques analysed does suggest that this is a limited problem within implementation of the SRP.

Four of the pairs showed patterns suggestive of therapist drift in relation to frequency of requesting, although in pair H this was only between the final two sessions. Three of these pairs also showed patterns suggestive of therapist drift in relation to task selection, although again in pair H this was only at the end of the study.

Drift occurred more in relation to adult-led techniques than child-led techniques. In contrast to the drift in requesting shown by four pairs, only one pair, pair K, showed a

pattern suggestive of therapist drift in relation to imitation. Therapist drift may have been higher in relation to requesting than imitation because it is easier to judge when to imitate the child's behaviour than when to make a request. If using the Son-Rise approach the parent should imitate both the child's stereotypical behaviour and echolalia, behaviours which are usually obvious and easy to notice. Requests are supposed to be made when the child is responsive, something which is perhaps more difficult to judge, as it may be indicated only by a fleeting glance from the child. It may thus be easier to maintain a constant level of imitation over time, whereas greater uncertainty over when to request may lead to more fluctuation in this technique.

Another factor which may lead to therapist drift in requesting is that parents may feel an increasing need to see progress in their child. By requesting more often they will give their child more opportunities to practice and demonstrate skills. This may be especially the case when filming sessions are carried out at regular intervals, as was the case with this study, since parents may feel the need to demonstrate the skills which the child has acquired since the previous session.

There was no evidence of therapist drift in relation to use of non-SRP techniques, type of request, praise or laughter, although for each technique there was a great deal of variation across sessions. Numerous factors may have contributed to such variation, including the mother's mood, the pair's activities prior to the session and the type of activities which the pair were involved in during the session. In addition the possibility cannot be ruled out that there were more subtle changes in some of these techniques over time indicative of therapist drift, but which were not measured within this study. For example, although the proportion of suggestions made by the mother as opposed to instructions remained relatively constant over time, suggestions may latterly have been made in a more directive tone of voice. The interview study, to be reported in the next chapter, explores the possibility of such changes.

It should be emphasised that while some of the patterns found were suggestive of therapist drift, they were not always absolute, and in a number of the pairs there were often one or two filming sessions which did not fit the overall pattern. Conclusions should therefore be drawn with caution. While patterns may have become more clear had filming been more frequent, this would have led to a scale of video analysis which was unmanageable within the scope of this thesis. It would also have placed an unreasonable demand on the families involved in the study. For example, if the number of filming sessions had been doubled, this would have meant fortnightly visits for a year to family K who had two children involved in the study. It was felt that this was too great an intrusion for a family who already had the pressure of running two Son-Rise Programs.

In three of the four pairs in which there were patterns suggestive of therapist drift the mother received ongoing 1:1 training during the period of the study. In two of the pairs, K and L, the training received by Mrs. K following session 2 appeared to prevent therapist drift developing further. Additional 1:1 training received by Mrs. K later in the study appeared to have less impact on therapist drift, although may have affected other aspects of SRP use. In the remaining pair who received ongoing training, pair H, training seemed to have been related to the beginning of therapist drift, rather than the prevention of it. However, in many of the sessions prior to training pair H had the lowest frequencies of requesting and task selection of any of the pairs in the study. The increases did not therefore make pair H's Program any more adult-led than many of the other pairs.

Ongoing 1:1 training may also have had an effect on other aspects of Program implementation. For example, training in pair L coincided with a sharp increase in the mother's use of praise for the child's own actions, and in pair J training coincided with an increase in Mrs. J's laughter.

The use of ongoing training seemed then to have been important in preventing therapist drift in at least one of the five mothers in the study, and may have had an effect on other aspects of SRP implementation in a further two mothers. The findings in Study 2 suggested that after the initial Start-Up course, parents' uptake of ongoing Son-Rise training was relatively poor. This, combined with the long waiting list for the Son-Rise Intensive training in the States and the lack of Son-Rise staff in the UK, may make it difficult for some parents to maintain a high level of intervention fidelity. However, while previous research has emphasized the importance of formal ongoing training for the maintenance of intervention fidelity (Moncher & Prinz, 1991), it may be the case that parents find that less formal methods, such as being given feedback from their spouse, are as helpful in this respect. Although such informal training may be beneficial, it is nonetheless important that those offering training in interventions are aware of the possibility of changes in technique implementation over time, and gear training accordingly.

The relationship between the mother's use of techniques and the child's behaviour was also explored in this study. It was predicted that variation in the adult's techniques over time would be related to the child's behaviour, with the adult adjusting their emphasis on imitation or requesting depending on how interactive the child was. On the whole though there were few obvious relationships found, including cases in which patterns suggestive of therapist drift had been found in relation to the adult's techniques.



Although there were relatively few relationships found, the most consistent finding was the positive relationship between stereotypical behaviour and imitation. This was as predicted, although the causal direction of the relationship cannot be determined. Word approximations were positively related to imitation in four of the six pairs, with a very strong relationship found in pair H. Imitation here seemed to serve two functions. For children for whom word approximations were the main form of communication, such as Harry and Jill, imitation seemed to be used to reinforce the child's attempt to vocalise. For children who had a sizeable vocabulary of proper words but who sometimes reverted to word approximations, such as George and Ian, these vocalisations were treated more as if they were echolalia, and imitated. While the former approach is not specified as an SRP technique, it seems similar to what might occur in any typical mother-infant interaction, and does not seem to go against the general principles of the SRP.

Relationships with maternal techniques were found less often for the other child behaviours, and where relationships did exist these were often weak and with conflicting findings across the pairs. It seems likely from this that the pattern of relationships between child behaviour and maternal technique is in fact very complicated. For example, it may be that while a child's behaviour, such as physical contact, reflects interactivity in some children, in others it may be a sign that they are less interactive. It is also likely that even in the same child a behaviour may signal interactivity at some times and non-interactivity at others. A good example of this is echolalia which can serve a number of different functions, including more interactive ones, such as requesting and turn-taking and less interactive ones, such as signaling distress or anxiety (Prizant & Duchan, 1981). This may mean that the adult would imitate the child's echolalia on some occasions and respond with a request on others. Such an inconsistency in response would explain why no clear relationship was found between echolalia and either maternal imitation or requesting.

It may also be the case that individual child behaviours did not seem to be related to maternal imitation or requesting because the mother responded to a number of the child's behaviours simultaneously. While the advantage of analysing the child's behaviours separately was that it helped to establish which behaviours were most closely related to the mother's techniques, it may be that stronger relationships between the child's behaviour and the mother's techniques would have been found if a combination of child behaviours had been examined together. The combination of behaviours that a mother responds to may include some that were not investigated within this study. Extending the range of behaviours analysed could therefore be helpful in clarifying the connections between child behaviour and maternal use of SRP techniques.

It would also be informative in the future to establish whether there was a change in balance between child-led and adult-led techniques used by the mother within a single session and if so, how these related to within-session changes in the child's behaviour. Preliminary analysis of this topic using the data from the present study suggests that in some sessions parents switch very rapidly from one technique to another in response to changes in the child's behaviour.

In summary then, this study found patterns of technique implementation suggestive of therapist drift in relation to only a limited number of techniques, and in only some of the parents using an SRP. Ongoing training seemed to limit the effect of therapist drift in one pair, as well as having an impact on other aspects of Program implementation in other pairs. Variation in the mother's use of imitation and requesting seemed to have been somewhat related to the child's stereotypical behaviour and word approximations in most of the pairs.

To explore these issues further, the five mothers involved in this study were interviewed after the final filming session. This interview study is reported in the following chapter. The interview study also explores additional issues, such as whether the mothers felt that the presence of an observer during the filming session affected their implementation of the Program and whether technique implementation is different in cases where the SRP is used with two children in one family, as was the case in family K.

The limited timescale of this thesis meant that a relatively small number of data points were produced for each mother-child pair in this study. Inference based on visual inspection of the graphical data was, therefore, the only appropriate method of analysis. However, if a replication study with more frequent filming sessions were undertaken it would be possible to conduct statistical analysis of the data, perhaps using an interrupted time-series analysis package such as ITSACORR (Crosbie, 1993). This would avoid the possibility of Type I errors associated with the interpretation of graphical data and would allow greater confidence to be placed in the findings (Crosbie, 1993). This procedure requires the data to be split into two 'phases': in this case perhaps a 'pre-training' and a 'post-training' phase to allow investigation of whether ongoing training affects intervention implementation. It also requires that each phase contains at least 5 data points, and ideally even more. It would therefore be important to ensure that the increase in frequency of filming required for such analysis did not place an unreasonable burden on the families involved in the study. Replication of the study with a larger sample would be additionally informative, in that it would allow investigation of issues such as whether the severity of the child's symptoms affects degree of therapist drift in the mother.

Pursuing investigation of intervention fidelity further is likely to prove fruitful. In particular it is important to identify the level of intervention fidelity required to produce an acceptable level of effectiveness, and to identify those techniques which must be implemented with a high degree of fidelity and those which can be less rigidly adhered to, or even omitted (Halle, 1998). In addition, such research could explore the possibility that for some techniques at least, a lower level of fidelity may produce a higher level of effectiveness.

However, a crucial question, and one which currently remains unanswered, is how is it possible to establish just when changes in the parents' techniques over time remain within the boundary of acceptable intervention fidelity and when they result in a level of fidelity which would be unacceptable within an evaluation. This problem exists within all the child-led interventions, possibly because these are, by their very nature, relatively unstructured and thus difficult interventions in which to apply measures of fidelity. More structured programmes such as the Lovaas approach, do not face these inherent difficulties to the same degree.

In terms of child-led interventions, it seems likely that applying arbitrary levels of required technique-use to satisfy fidelity requirements would be unhelpful. Instead it may be more useful to measure intervention fidelity by considering the mother's techniques in relation to the child's behaviour - for example, examining the proportion of the child's stereotypical behaviour which the mother imitates. The finding within this study - that in pair H, although the mother's use of imitation in session 1 seemed to occupy a small percentage of the session, the proportion of the child's vocal and stereotypical behaviour imitated was incredibly high - emphasises the value of considering intervention fidelity in relation to the child's behaviour, rather than as a stand-alone measure.

It may also be helpful to consider the proportion of child-led versus adult-led techniques, such as task selection. In child-led interventions a higher proportion of child-led than adult-led techniques would be expected. Considering use of techniques which go against the ethos of the intervention, such as the non-SRP techniques examined in this study, is also likely to be helpful in establishing intervention fidelity.

These are all possibilities. However, until the question of how to establish acceptable levels of intervention fidelity are resolved, evaluation studies of child-led interventions such as the SRP will be of limited validity. If it is impossible to judge whether the Program is applied accurately, then it is impossible to say with certainty that any changes

found in the child's behaviour in an evaluation study are due to the application of the SRP.

## **7.7 Overview**

The present study explored notions of intervention fidelity and therapist drift in relation to the SRP. Initial intervention fidelity, as far as it could be measured, seemed high in four of the six mother-child pairs studied, and while there was some evidence of therapist drift this was limited to only some of the techniques and did not occur in all of the pairs. Training seemed to be associated with prevention of therapist drift in one case. The interview study, to be reported in the next chapter, seeks to explore these issues further, but from the perspective of the mothers who were involved in the video analysis study.

## CHAPTER 8

### STUDY 5. PARENTS' IMPLEMENTATION OF THE SON- RISE PROGRAM: VIDEO REVIEW AND INTERVIEW STUDY

#### 8.1 Introduction

In this chapter an interview study involving the five mothers who participated in the previous study is reported. This was carried out at the end of the data collection period for Study 4, with the aim of exploring whether the mothers themselves felt that there had been any changes in technique implementation over time, and if so what they felt were the reasons for this. It was hoped that an interview study would both offer another perspective on the data used in Study 4, and allow the findings to be explored in greater depth.

In Chapter 7 it was found that there were patterns suggestive of therapist drift in four of the six pairs, although this was in relation to a limited number of techniques, requesting and task selection in particular. If, when interviewed, the mothers described a pattern of change over time which is consistent with these findings, this would lend additional support to the conclusions drawn in Study 4.

Although the video analysis in Study 4 demonstrated patterns suggestive of therapist drift in some of the pairs, it could not explain why these patterns occurred. Was it because the mothers were uncertain of the correct techniques, or was it a conscious decision to change the way the Program was implemented to better suit the child? An interview study has the potential to provide an explanation, from the mothers' perspective, of why these changes had occurred, if indeed they were to describe a similar pattern of change over time to the one found in the video analysis.

Study 4 examined changes in a wide range of techniques over time. However, an interview study might expand on this by identifying further areas in which the mothers felt there had been change. In particular, because Study 4 focused on quantitative change over time an interview study could be helpful in providing an insight into any additional qualitative changes that mothers felt had occurred.

The previous study also found that ongoing 1:1 training seemed to influence implementation of the Son-Rise techniques. In two of the six pairs it appeared to halt the occurrence of therapist drift and in other cases training was followed by an increase in praise or laughter in therapy sessions. Pair I, who received no ongoing 1:1 training, had the most adult-led approach throughout the year. However, while the video analysis showed an association between ongoing 1:1 training and implementation of Son-Rise techniques, it could not be conclusively shown that training was responsible for the changes. Although uptake of training was followed in some cases by a change in the frequency with which a technique was implemented, the possibility that events or circumstances other than training brought about this change cannot be ruled out. Interviewing the mothers should help to clarify how they felt that training had influenced their technique implementation, if at all.

In Study 4 the possibility was raised that the presence of an observer and camera in the playroom may have influenced the way in which the mothers implemented the techniques during those sessions, perhaps leading to an underestimation of therapist drift. Again, asking mothers directly whether they felt being filmed affected them might help clarify the extent to which this is a methodological problem which should be considered in research of this type.

## **8.2 Research topics**

The interview study to be reported in this chapter explored the mothers' views on their Son-Rise technique implementation during their first year of using the Program, i.e. the data collection period of Study 4.

The following questions were explored in relation to the mothers' use of requesting, imitation, praise and the 3Es:

- Did the mothers note the same variations in these techniques over time as found in the video analysis in Study 4?
- Did they feel that there had been any other changes over time in their use of these techniques?
- What did they feel were the reasons for any changes over time which occurred?
- Did they feel ongoing training affected their implementation of these techniques?

As the interviews were carried out prior to identification of task selection and non-SRP techniques as behaviours which could be incorporated into the video analysis behavioural categories, these were not included in the interview schedule. However, because both requesting and imitation were included, the change in both adult-led and child-led techniques over time were open to exploration.

Additional topics which were covered included:

- Changes in additional techniques not explored in Study 4.
- The experience of using the Program with two children (pair K).
- The experience of moving from the SRP to the Lovaas approach (pair I).
- The perceived affect of the presence of the camera and observer in Study 4.

### **8.3 Methodology**

The five mothers were interviewed at the end of the data collection period for Study 4. This was done as soon as was convenient thereafter in order to ensure that the events of the year would still be fresh in the mothers' minds. Mrs. K was interviewed on two occasions, once in relation to her SRP with Kevin and once in relation to Laura. Each of the interviews lasted around two hours, and was tape recorded. The interviews were later transcribed and analysed using a similar 'grounded theory' approach to that used in Study 3 (see page 154). At the beginning of each interview the mother signed a consent form stating that she was agreeable to the interview being recorded. Details of this and other ethical considerations can be found in Appendix A.

The taped interview was in two parts. In the first section the mothers were shown 5 minute video clips taken from the middle of each of their 7 filmed sessions. The mothers were asked to discuss each clip in turn, in particular commenting on their implementation of the SRP techniques at that point. It was hoped that the video clips would act as a memory aid, given that the mothers were being asked to discuss events that occurred up to a year prior to the interview.

The second part of the interview was more structured and contained questions on the mothers' implementation of the Son-Rise techniques over the year, any changes in their child's behaviour, and whether the mothers felt ongoing training had had any effect on their implementation of the Program (for full interview schedule, see Appendix G). In addition, the mothers were asked whether they felt the presence of an observer with a camera had made any difference to how they behaved in the therapy room and, if so, whether this had changed over the year.

Given that the type of questions chosen for inclusion in the second part of the interview would inevitably been influenced by the author's opinions on how the mother's technique use changed over time in Study 4, the less structured style of the first part was designed to counterbalance this potential source of bias.

## **8.4 Interview findings**

### **8.4.1 Requesting**

In Study 4, therapist drift in relation to requesting had been seen in pairs I, K and L, and also in pair H in the final session. In all cases the pattern of change described by the mother in the video review and interview matched the pattern found in Study 4.

In the case of pair I, who had shown a pattern of increasing requesting over time in Study 4, Mrs. I commented as she watched the video clips that she felt that over time she had increasingly set the agenda and made requests. After watching the clip of session 3 she commented "I think by then I was still following him, but more trying to get him to do what I wanted him to do." By session 4 the family had removed the trampoline from the room and put in a table with the intention of doing more tabletop work. She commented that by that stage she had moved away from following him and was setting the agenda. In contrast to the lack of association between Ian's behaviour and Mrs. I's use of requesting in Study 4's video analysis, Mrs. I said that her increased requesting over time had come about because she felt that Ian had become more interactive over time and could therefore cope with an increased level of requesting. She felt that this change in him also meant that he required more academic input, which is one of the reasons why she changed to the Lovaas approach.



Mrs. K in Study 4 had shown an initially high level of requesting in relation to both Kevin and Laura, which decreased after training, and then gradually increased again. Again, the pattern of change described by Mrs. K in the interview matched that found in Study 4. She felt that her level of requesting had initially been too high, particularly with Kevin, and that in retrospect this had been due to her uncertainty about the correct way to implement the techniques. She commented that she often requested at times when it may have been better to imitate. She felt that her first visit to the Option Institute with Kevin had had an enormous effect on her use of the techniques with both children. After the visit she spent a period of several months with Kevin and Laura really focusing on the 'bonding through acceptance' side of Son-Rise, concentrating on imitation, and reducing the number of requests for a time until she felt that the children had a "solid foundation" of acceptance and trust. Following this, she described how she began to increase the level of requesting with both children, because she felt that they had become more interactive. Again, as with Mrs. I, this is in contrast to Study 4 which had shown few obvious links between the child's behaviour and the increase in requesting. However, Mrs. K commented that she felt this increased interactivity was partly shown through the children being more attentive to the joint activities, a behaviour which was not measured in Study 4.

In pair H, Study 4 showed a comparatively low level of requesting throughout until the final session. Mrs. H also felt that her level of requesting had been low for a long time, but she felt that it had been too low, and that in earlier sessions she had missed a lot of opportunities where Harry was interactive and motivated and she could have made a request. The reason for this was that she had experienced difficulty maintaining the fun, playful aspect of the SRP whilst asking Harry to do something. As she wanted Harry to perceive the playroom as an enjoyable place to be, she therefore limited the number of requests she made:

*"I felt that requesting had to be kind of somehow strict or stern. I mean I'd still say 'Oh I love you and I know you can do it', but its still the kind of finger pointing. And so therefore I think I didn't do it as much because it didn't feel right doing it that way." (Mrs. H)*

When watching the clip of session 6 she commented that she felt her level of requesting had increased, and that it further increased after a training session prior to session 7, which had taught her how to request in a more fun way. Thereafter she felt more comfortable making

requests and so increased how often she made them. Far from being therapist drift, therefore, the pattern of change which Mrs. H described was one of increased rather than decreased intervention fidelity in the final two sessions. Although her level of requesting had increased she felt that this brought it from a level which was too low to one that was appropriate, and that she had learned to make the requests in a manner which corresponded more closely with the ethos of the SRP.

In terms of other changes over time related to requesting, all of the mothers, except Mrs. H commented that, in retrospect, they had experienced difficulty with the timing of their requests when they began the SRP. Mrs. G, Mrs. J and Mrs. K commented specifically that the difficulty was that they often made requests at times when the child was withdrawn and it would have been more appropriate to imitate. Partly this was because they were not as aware of the signs from the child, such as eye contact and attentiveness, that signalled an appropriate moment for interaction, but largely it was a desire to bring the child out of a withdrawn phase (or 'exclusive phase' as it is termed in the Son-Rise literature):

*"I think early on you feel - and you see this with the volunteers when they're first starting - it's feeling like you have to entertain him, like you have to get him to move onto something else if he's just being withdrawn." (Mrs. G)*

*"Before I was frightened of her being exclusive. 'Oh my God I've got to get her back, I've got to get her attention back. She's bored, she's going to want out of the room.' Whereas now it's not a problem, not an issue any more, and if she's being exclusive she's being exclusive." (Mrs. J)*

*"Although I was doing the same thing as him, I wasn't actually enjoying what he was doing, I was more doing the same thing as him with the intention of 'hey, hey let's do something else.'" (Mrs. K)*

As with Mrs. H, two of the other mothers, Mrs. G and Mrs. J, commented that initially they felt that they made requests in a way which were not as much fun for the child. Mrs. G said:

*"It was like making him jump through hoops to get what he wanted, rather than making it fun for him to want to do it and get what he wanted." (Mrs. G)*

All three mothers learnt through further Son-Rise training to continue enjoying the activity in hand whilst making requests. Mrs. J commented on the effectiveness of this:

*“To get what you want, which is language and interaction, jumping through hoops you don’t get these, whereas if we just go and play with her, we get everything that we want, but its a by-product of what we’re doing, its not the focus. I’m not going in there like ‘I’m going to teach her this and this and that.’ It’s a case of ‘I’m going in there to play with her’ and we’re getting all that stuff without pushing, without focusing, and because now we’re playing in a more fun way she’s willing to do anything you want.” (Mrs. J)*

#### **8.4.2 Imitation**

In Study 4 pair K had been the only pair in which a pattern suggestive of therapist drift had been found in relation to imitation, with imitation initially low, increasing following training, and then gradually decreasing again. The pattern described by Mrs. K during the video review and interview again matched the findings in Study 4. The reason for the changes over time are similar to those described in the requesting section above. She felt that prior to their first visit to the Option Institute she had, in retrospect, been uncertain of the correct way to use imitation, and had therefore not imitated enough, and often made a request or introduced a task before she had been imitating for any length of time. Her visit to the States had made an enormous difference to her understanding of what a fundamental part of the SRP imitation was and her belief that a message of acceptance can be conveyed through imitation. Following this she really focused on imitation and dropped her level of requesting for a time:

*“We just wanted to give him a good grounding at that stage so that he could tell that he was being accepted for who he was, and I felt that previously he hadn’t had that base – that we accepted him and would be with him. If he did spit at the mirror or bounce on the ball then that was okay, we didn’t have to say ‘hey what are we going to do next?’ It was okay for him to do that for as long as he wanted to do it. Personally I don’t think we started the Program till we got back from the States.”*  
(Mrs. K)

Following this Mrs. K gradually began to introduce more requesting and be somewhat less focused on the imitation, which she felt was balanced by the fact the Kevin had become more interactive. Mrs. K strongly felt that her training at the Option Institute had made a vital change to the way in which she implemented this aspect of the Program.

The majority of references made to imitation of the child in the interviews with the mothers related more to qualitative rather than quantitative changes over time. For example, both Mrs. G and Mrs. K felt that following training they had a better understanding of how to use imitation to form a deep connection with the child rather than as a superficial technique, in which they simply copied the child, without really 'getting into' what he or she was doing. Both felt this had enabled them to enjoy imitating their child's 'isms' (stereotypical/repetitive behaviour) more:

*"In session 7 we were having this book waving ism thing and we had a really great time doing the ism, and it wasn't just copying, it was really enjoying it yourself...His isms have become more fun instead of 'oh my god here we go again with that thing' which it felt a bit like before, and I think it's a revelation to me that isms can be fun."* (Mrs. G)

Mrs. K noted that when she returned from the first visit to the Option Institute her imitation of both Kevin and Laura was very exact, to try and give the children a real feeling of trust and acceptance. Following her second visit to the States she began to gradually change this so that although she was still imitating, it varied slightly from what the children were doing. This was partly so that Laura could learn to cope with some change from routine, but mainly to make it more exciting, both for the child and for herself and the volunteers. She felt that adding variation would make the volunteers more enthusiastic about what they were doing and she felt that the children sensed this sense of enjoyment. Mrs. G did the same thing following video-feedback training prior to session 7 and said that she felt that this meant that the imitation turned into an interactive game more often.

One difficulty that both Mrs. G and Mrs. J had experienced was in knowing which behaviours to imitate. They felt that while their child's stereotypical behaviour was easy to identify knowing which of their behaviours were repetitive routines was more difficult. While both were behaviours that they might wish to imitate, the latter were difficult to spot:

*"I think it took me a long time to recognise that some of his things are isms, that maybe you think are games, but they're not really games. I mean things like ten in the bed, he used to do that again and again and we thought well what a cute game but actually that was an ism, it was just a different kind of ism. I think from the Start-Up I hadn't really got the hang of the fact that an ism isn't just hand flapping or book waving or something like that, that an ism can be ten in the bed. He's interactive-ish doing it but it is an ism, it's still a repetitive thing."* (Mrs. G)

### 8.4.3 Praise and the 3Es

Praise and the 3Es will be discussed together because the comments that parents made in relation to the two techniques overlapped a great deal. Note that although mother's laughter was examined in Study 4, it was the 3E's – energy, excitement and enthusiasm – that was discussed in the interviews.

In Study 4 neither praise nor laughter had shown therapist drift, that is a decrease over time. Instead the pattern of fluctuations in each had been very variable. In contrast, the mothers all felt that their level of praising and/or the 3E's had been relatively low until they received further training, and that their praise level in particular was generally higher at the end of the year than at the beginning. As with the parents in Studies 2 and 3 the mothers in this study identified the 3Es as a particular area of difficulty.

Several of the mothers commented that, although they had praised their child, in retrospect this had not been frequent or enthusiastic enough, particularly in relation to eye contact and language, and that sometimes their praise came out as more of a commentary. All of the mothers except Mrs. K commented that, while praise and enthusiasm came easily at times when the child was interactive, it was more difficult to maintain at times when the child was withdrawn:

*"I was enthusiastic, I thought it [the Son-Rise Program] was the best thing. I just didn't appreciate when to be enthusiastic, until I got it into my head that you've got to be enthusiastic all the time, and it wasn't only when you get this word and when she's doing something."* (Mrs. J)

Mrs. H and Mrs. J also felt that in the earlier sessions although they often praised their child's big achievements it was more difficult to remember to praise for the smaller things:

*"Recently I've started doing that more as well, like any little thing saying thank you for it a lot more. For anything you know, a little glance. [Previously] I wouldn't give praise unless I considered it a bigger thing, as opposed to stuff that maybe he's been doing for 6 months and I've just taken it for granted. I think I could have been a lot more liberal with my praise."* (Mrs. H)

In Study 4, 1:1 training had been associated with an increase in praise (pair L) and laughter (pair J) although, as both of these showed a general upward trend over time anyway, it was difficult to ascertain the effect that training had had. In interviews it was found that for all the mothers training had had much more of an impact on these techniques than Study 4 had suggested. The mothers all commented that training, either 1:1 teaching, video-feedback or the Maximum Impact had helped them increase their 3Es and, for a number of mothers, also their level of praise. In some cases this was due to a general motivational boost and in others, such as Mrs. K, because they were specifically taught to praise more often, in her case for eye contact. In the case of Mrs. G it was a recommended change in the playroom environment during video-feedback prior to session 7 which led to increased enthusiasm as a by-product. It was suggested to her that George was using the many toys in the room as a means of avoiding interaction. Mrs. G duly removed most of the toys from the room and instead only had about 3 in at a time which were changed regularly. She felt that this helped George because he became more focused on the interaction with the adult rather than the toys. It also gave the program more variability and thus helped increase her 3Es:

*“Every day’s different, I think the problem was previously, he’d have these isms that had been going on for months and months and, with the best will in the world, you do get fed up of it, you get fed up with him rolling a car around the floor again. Whereas now for a start he’s not doing as much isming and secondly the isms are variable so it’s not like the same car or whatever for the millionth time. You should obviously be accepting, but it does get hard because you’re bored with it really, and I think that he was actually bored with it too.”* (Mrs. G)

Mrs. H, J, and K all commented on how an increase in the 3Es and praising following training had an obvious effect in their child, in terms of increased eye contact, interaction and language. Mrs. H, who received 1:1 training between sessions 6 and 7 commented that this change made her wish she had had the training sooner:

*“I have this feeling that it was going okay but it could have done with a little injection of enthusiasm or excitement or a bit more zip, which may have turned him on to try more because just the difference between sessions 6 and 7, I mean I haven’t seen the whole thing, but he was so much more vocal in that short space of time and giving so much more. It makes me go ‘okay what might have happened six months ago if we’d had a bit more zip?’”* (Mrs. H)

In the interviews Mrs. K described some more qualitative changes which had occurred over time in relation to her use of praising. On her first visit to the Option Institute she noted that some of the staff would give Kevin an explanation of why they were praising him. For example, one of the staff had praised Kevin for making eye contact and explained that friends make eye contact with each other. Following this Mrs. K had tried sometimes to include an explanation of why she was praising Kevin or Laura, to help them understand the social significance of the skills they were learning.

Another qualitative change that Mrs. K noted was that towards the end of the study, in order to avoid the praise becoming monotonous, she had looked for alternative ways to show Kevin and Laura that she appreciated their eye contact. For example, she would try to express appreciation through her facial expression and would become especially interested in what the children were saying when they were making eye contact. Future studies examining intervention fidelity should perhaps take into account that appreciation of the child's actions may not always be expressed verbally.

#### **8.4.4 Changes in additional techniques**

Using the information from the first part of the interview it was possible to explore whether the mothers felt there had been changes in any additional techniques not investigated in Study 4. Both Mrs. J and Mrs. K felt that over time they had increased how much, and how quickly, they responded to their children's language. They felt that this had helped the children understand that language created an effect and was an effective way of getting a desired object. For Mrs. K this was learnt on her second visit to the Option Institute, and she felt that this was the most important change in her use of the Program as a result of that visit. Mrs. J felt that experience of using the Program and watching her SRP sessions on video led to her increased responsiveness.

Mrs. K commented that her awareness of her own positioning in relation to Laura when she was in the playroom was also something which had changed as a result of training at the Option Institute. She learnt how to position herself at a lower level than Laura, to make it easier for her to make eye contact. She also learnt to vary the distance that she sat from Laura, and she found that if she sometimes sat a bit further away it gave Laura some space and seemed to make her more likely to initiate interaction.

Mrs. G felt that an important change in her use of the SRP, as a result of a support phone call, was her realisation of how often she and her volunteers introduced games such as 'ten in the bed' which they knew George enjoyed, but which ended up being playing repetitively and were rarely expanded on. She felt that this was something they did because they were not totally comfortable with George's withdrawn periods and felt a need to keep him 'entertained', but they came to understand that allowing more original games to develop from George's own actions was preferable because this encouraged variety rather than repetitiveness in George's behaviour.

The mothers all felt that, on the whole, they had applied the Son-Rise techniques in an accurate and effective manner. Mrs. G and Mrs. H, however, both commented that initially the Program had seemed quite clear and the way in which to implement the techniques straightforward, but that after a few months of applying the Program they realised that it was not quite as easy as they had first thought. All of the mothers expressed their opinion that use of the SRP had been a continual learning process for them over the year.

#### **8.4.5 Ongoing training**

In Study 4 it was found that training seemed to be effective in improving the technique implementation of Mrs. K in relation to requesting with Kevin and Laura and to imitation with Kevin. Training may also have been connected with an increase in praise in pair L and laughter in pair J, although the evidence for this was very limited.

Although some associations were found in Study 4, the influence that training had on correct technique implementation came across much more strongly in the interview study. All of the mothers, except Mrs. I, commented that use of ongoing training was vital to ensure correct technique implementation. While the mothers felt that their use of the SRP had changed as a result of experience they also mentioned numerous ways in which their implementation of the techniques had changed as a result of training. Although the mothers found that methods of ongoing training which involved them being observed were most beneficial (as has been previously reported in the literature), in some cases even the use of support phone calls made an enormous difference to their SRP:



*"I think one thing that's quite interesting just watching all these [video clips], how important it was to have contact with America through the phone calls, because its all very well doing the Start-Up course, but we were running into problems in several ways and every time you've been asking me 'why did you change?' most of the time I've been saying because we asked the Option Institute." (Mrs. G)*

*"Personally I really don't think we started the Program until we got back from the States. I mean I know there are no rights and wrongs, but I don't think we really fully understood joining before we went and joining is the basis of the whole Program. So really that's why I say I don't think we got started until we came back. I would recommend to anyone that goes on the Start-Up and thinks that they can do it from the book to go to the States." (Mrs. K)*

Mrs. J and Mrs. H commented that even if the Program is going well it can be very reassuring to have this confirmed by the Son-Rise staff. Mrs. J felt that this confirmation had made her feel more relaxed and focused in the playroom.

Mrs. H felt that use of ongoing training would be particularly useful for parents who, as she did, had other children and an exceptionally busy family life. She felt that this meant that she had little time to reflect on her own methods of technique implementation:

*"To maintain the program and keep it going I think support from the Option Institute is vital, particularly for me with 5 children. Perhaps if I only had one other child, I might have the ability to have the time to think about these things more and work them out more for myself with the basis of the underlying philosophy, but I don't have that time, I don't have the luxury of trying to figure it out." (Mrs. H)*

All four of these mothers felt that, in retrospect, they wished they had made more use of the support services and, although they were expensive, it was a false economy not to use them because of the difference they made in how effectively the Program could be run:

*"I think anybody that wants to do Options and just does the Start-Up and thinks they know what they're doing is going to run into bother. I don't think we made proper enough use of the support services early enough on, because it was so expensive and because I think I naively thought I knew what I was doing, and also because at the beginning it took time to set up the playroom, it took time to get the volunteers, and it seemed like, 'let's get going first'. But once I started using it I think I really realised the value." (Mrs. G)*

Although the mothers found all types of support services useful, there was a general consensus that a 1:1 training session, either in the States or from a UK-based member of the Son-Rise staff, was the most helpful. As in Study 3, several of the mothers commented on the need for more trained Son-Rise staff in the UK. The mothers commented that after 1:1 training, sending over a video of a Son-Rise session was the next most helpful approach to training; Mrs. H commented that for her any feedback which involved 1:1 observation with a member of the Son-Rise staff was useful because sometimes there were difficulties which she was not aware enough of to ask a question during a phone consultation:

*"I mean, seeing a member of the Son-Rise staff working with Harry made such a huge difference. There was a lot of things I was learning this last year and had questions on and then suddenly seeing her in action had a huge impact, because I'm aware that I'm maybe not always good at translating how I feel into words, so actually seeing someone else doing things answered so many questions that I wasn't really aware that I had. I just knew it wasn't working right, but I didn't know how." (Mrs. H)*

Mrs. G, H, J and K mentioned a number of additional methods which they had found useful in helping them maintain correct implementation of the Son-Rise techniques. Mrs. G, H and J found that observing and giving feedback to their volunteers was helpful because, on some occasions they found that the suggestions they offered the volunteers were ones which they could also make use of themselves. Mrs. G commented that just watching the Program from the position of an outside observer often clarified issues for her. Mrs. J and Mrs. K also found that watching videos of others working with their child, either volunteers or trained Son-Rise staff, was also helpful in this respect.

Mrs. G and Mrs. I had not received any 1:1 training during the study. Mrs. G though had made use of the support phonecalls on four occasions, and video-feedback once. In comparison Mrs. I, who had a relatively high use of adult-led techniques throughout the study, had only made use of the support phonecalls on one occasion. This was towards the end of her time implementing the SRP, by which time she felt that she had become very uncertain of how to implement certain aspects such as requesting. She commented that the phonecall had been unhelpful because it had not clarified this area of concern for her, and she felt that she required more structured advice:

*"I think we phoned them because we were stuck, where do we go from here sort of thing, and they had just sort of said challenge him, you have to decide yourself when is the best time to challenge him, and to get him to do things, but we were still never very clear after the conversation, like what kinds of things to get him to do, and how to get him to do things. We were still not very clear. I just couldn't understand what they meant by some things...we weren't any further forward after the phone call. It didn't really encourage us by saying 'this is what you've got to do, that is what you've got to do.'"* (Mrs. I)

With this one exception, the mothers had found ongoing training to be very beneficial and were generally of the opinion that a Program could not be run effectively without it.

#### **8.4.6 Family K – implementing the program with two children**

One issue raised in the previous study arose from the fact that one of the mothers, Mrs. K, was using the Program with two of her children, Kevin and Laura. Of particular interest was the extent to which training with one child influenced technique implementation with the other. In Study 4 it was found that, while the first visit to the Option Institute with Kevin was associated with a change in the use of techniques, in particular requesting, with both children, a subsequent visit with Laura did not appear to be associated with changes in technique application with Kevin. Frequency with which techniques were used also seemed to differ between the pairs.

When interviewed Mrs. K commented that, although she felt that she had applied the Son-Rise principles of acceptance and respect for the child's wishes in the same way with each child, she was very different in Son-Rise sessions with Kevin from her sessions with Laura. For example, she mentioned differences in the type of things she would ask each child to do when she made a request, and differences in the way she responded to eye contact from each child. Nonetheless, Mrs. K did indicate that ways in which she learnt to improve her technique implementation during training were often applied to both children. As in the findings of Study 4, this was particularly noticeable in relation to what she had learnt about joining and requesting on her first visit to the Option Institute with Kevin.

#### 8.4.7 Family I – moving from the SRP to Lovaas

In Study 4 the program used in pair I had seemed to have a relatively strong emphasis on adult-led techniques, with an increasingly high degree of adult task selection and requesting over time. By session 6 the family had switched to using the Lovaas approach, and the interview with Mrs. I explored why she had made this decision, and what her experience of implementing the SRP had been prior to the change.

Mrs. I felt that, although she was somewhat unsure of how to react to Ian's challenging behaviour, on the whole she had been initially fairly confident about her use of the Program, particularly aspects such as joining in with Ian's activities and encouraging him to make eye contact. However, as time went on, although she had taken the lead more and made more requests, she experienced difficulties in relation to how she should go about this. She found the lack of structure in the SRP made it difficult for her to implement:

*"I think that's where Options falls down, because there isn't anything set out for you to follow, you know you've just got to go with your own instincts, when to do things, when to challenge, and I found that very difficult. I really did find that hard, when to do it, and what to do." (Mrs. I)*

As the results from Study 4 suggested, Mrs. I did feel more confident using a more didactic, prescribed approach:

*"I think I was more confident with Lovaas, because you're following programmes, you know what you're doing, and there's only 3 steps to the way you work at the table. So I felt a lot more confident doing it this way than I did with Options. I mean when I started Options it was fine, because I used to just follow him and play with him and do whatever he wanted to do, but as I say when it got nearer the end of the year we knew that he was ready to do something more, but we were stuck, we didn't know where to go from there – it got harder then." (Mrs. I)*

However, she did stress that she had greatly enjoyed using the SRP and that she had found it very beneficial in helping Ian become more interactive. She felt that without it he would not have been receptive to the more didactic approach of Lovaas.

#### 8.4.8 Effect of the camera and observer

A concern raised in the previous study was that the mothers may have behaved differently in Son-Rise sessions that were filmed, to how they would normally interact in the playroom. Previous research indicates that awareness of being observed increases adherence to correct procedures (Taplin & Reid, 1973). The incidence of therapist drift found through the video analysis would then be somewhat lower than actually occurs if the parents implemented the techniques with a higher degree of fidelity during filming sessions than they did during their normal sessions (Gresham, *et al*, 1993). The fact that mothers were aware that the observer was trained in the use of the SRP may have increased the chances of this. Although the mothers were instructed to behave as they normally would during the filming sessions, they may nonetheless have behaved differently in some respect.

Indeed it was the case that two of the mothers, Mrs. G and Mrs. H, felt that the presence of an observer had made them more aware of their techniques and kept them more focused:

*"I think it makes you more on your toes and I had noticed that every time you came to film I came out of the room feeling that it had been an effective session, or a good session. I don't mean by good that he was necessarily interactive, but that I had responded to him appropriately and I had been present and all the rest. I think that it's the being present thing that makes the big difference having someone else there, because you're not going to sit there and look at your watch and wonder what you're going to make for the tea if there's someone there filming you."*

(Mrs. G)

Most of the other mothers also felt that the presence of the camera and observer had affected them in some way at some stage. Mrs. K and Mrs. I felt that initially it made them feel somewhat nervous and self-conscious, which continued throughout the study for Mrs. I who commented that it made her worry about whether she was implementing the Program correctly. However, Mrs. K noted that latterly, as she gained confidence in her use of the SRP, she became much less aware of the camera. Mrs. J felt that in some of the sessions, in particular the last one, the presence of the camera made her want to elicit an optimal performance from Jill, which may have increased her use of requesting. This may explain the increase in original requests found in the video analysis of session 7 in pair J, compared to their previous five sessions.

## 8.5 Discussion

The interviews conducted with the five mothers who had participated in Study 4 provided an opportunity to explore whether they themselves felt that their implementation of the Son-Rise techniques had changed over time during their first year of use. It also expanded on Study 4 by examining the reasons why any changes in technique use over time might have occurred.

The interviews seemed to confirm the patterns of therapist drift which had been found in the previous study. In all cases, where a pattern of therapist drift had been found in the video analysis the mother described the same pattern of fluctuations when reviewing the video records and when interviewed. This triangulation strengthens the findings of both Study 4 and the suggestions of therapist drift made by Jordan and Powell (1996).

The fact that the interviews were conducted prior to the video analysis for Study 4 strengthens the finding that both studies revealed patterns of therapist drift, as it means that the results of Study 4 did not influence the manner in which the interviews were conducted. Although the findings of the interview study could, in theory, have influenced the patterns of therapist drift found in the video analysis, the use of a second observer to confirm inter-rater reliability in Study 4 reduces this possibility. The findings of the two studies were therefore as independent as was possible in two studies conducted by the same person.

There seemed to be two main reasons why the parents' use of the techniques changed over time. Firstly, it was because they learnt through additional training that their application of the techniques prior to training could in some way be improved upon. This was the case in pairs K and L, who had an initially high level of requesting. Following training the mother adjusted her use of the Program to emphasise the child-led techniques more. The second reason that parents gave for a change in technique use over time was that they had adapted the Program to correspond with development in their child. In all cases this was a change from an emphasis on child-led techniques to adult-led ones because the parents felt the child had become more interactive and therefore better able to cope with a heavier emphasis on the 'inspiring growth' side of Son-Rise. Pairs I, K and L all reported this pattern of change.

The findings from the interview study suggest that changes in the child's behaviour influenced changes in the mothers' use of techniques to a greater degree than had been suggested in Study 4. A possible reason for the different findings in the two studies is that, although the children had become more interactive over time, leading the parents to use more requesting, this was not found in Study 4 because the behaviour of the mothers and children during the filmed sessions was different to how they normally interacted when in the playroom. An alternative explanation is that, although the children had become more interactive over time, this was indicated by a change in behaviours other than the ones chosen for video analysis in the previous study. Mrs. K, for example, mentioned that Kevin had become more attentive to shared activities, a behaviour which had not been examined in the video analysis. Although a wide range of child behaviours was examined in Study 4, it may therefore be advantageous to expand these even further in future studies of therapist drift.

While training seemed to have some association with change in technique implementation in the previous study it came across as being even more influential in the interviews, with four of the five mothers stressing how important they felt it was for effective use of the Program. This supports previous literature emphasising the importance of ongoing training in preventing therapist drift (Moncher & Prinz, 1991). An additional question to be explored in the future is how frequent this training needs to be to maintain the important aspects of treatment delivery. Gath (1979) notes that a balance must be obtained between training which is frequent enough to support the parents and training which is too frequent and increases the parents' dependency on the trainer, thereby discouraging them from finding ways to solve their own difficulties in intervention implementation. In practice the level of training required is likely to vary across parents.

As previous research suggested, parents found 1:1 training the most beneficial, although they found all types of ongoing support helpful in ensuring the SRP techniques were correctly implemented. Future studies of therapist drift should therefore document all types of ongoing training so that their influence on technique implementation can be monitored. This would though place greater demands on the parents participating in the study, as they would have to be involved in recording the content and timing of all ongoing training. Care would therefore have

to be taken that this did not place excessive demands on parents who were already coping with running an SRP and raising a child with autism.

An interesting finding from this study was that, although the changes in requesting over time in pair H described by Mrs. H matched the changes found in Study 4, this pattern was interpreted very differently in the two studies. While in Study 4 it had been interpreted as being suggestive of therapist drift, in the interview study Mrs. H described how the change had taken requesting from a frequency which was too low to one which was more appropriate, thereby increasing rather than decreasing intervention fidelity. This difference highlights the benefits of investigating intervention fidelity from more than one viewpoint. It also emphasises the difficulty, described in the previous chapter, in seeking to establish intervention fidelity in an intervention such as Son-Rise which is only semi-structured. The Son-Rise principle of adapting the emphasis on the various techniques according to the child makes it impossible to state how frequently a technique should be used. This therefore makes it difficult to state whether a change in technique over time has taken it from an acceptable level to one that is too high, or from a level that is too low to one that is acceptable. While establishing intervention fidelity is always likely to be problematic in the child-led interventions, continuing to develop research designs which measure technique implementation with reference to changes in the child's behaviour will probably be the most practical way of assessing intervention fidelity.

With regards to the effect of the presence of an observer on the mothers' implementation of techniques, the findings from this study are consistent with previous literature, in that some of the mothers felt that they had implemented some of the intervention techniques more accurately when they were being observed. While steps recommended in the literature were taken to minimise this effect, such as the observer trying to be as unobtrusive as possible, Gresham (1996) comments that, on the whole, this difficulty is inevitable in research of this type.

It is acknowledged that this interview study provided only the mothers' perspective on the SRPs in the families involved, and that other family members involved in the Program may have had a different view on how it had changed over the course of the year. This study did though seek the views of those who were most knowledgeable about the mother's implementation of the



techniques – the mothers themselves. Their views were instrumental both in confirming the results of the previous study and expanding upon them.

The interviews conducted in Study 5 add to the previous studies in this thesis in exploring the ways in which families implement the SRP, and how they adapt their use of it over time. The resulting picture is one of constantly changing intervention use, and adaptation of the SRP by each family to suit their own child and family circumstances. The following chapter draws together the findings of all the studies in this thesis, and explores their implications.

# CHAPTER 9

## CONCLUSIONS

### 9.1 Introduction

This thesis set out to explore two areas which have, to date, been somewhat neglected in the field of autism intervention research. The first is the effect on the family when parents become involved in interventions with their child with autism, and the second is the prerequisites necessary for evaluating such interventions. Both of these topics were explored in relation to the Son-Rise Program, an increasingly popular, but under researched parent-run intervention.

This thesis explored the two themes through a series of five inter-linked studies, the results of which will be drawn together in this chapter. The aim is not to simply reiterate the discussion sections of each of the studies, but rather to pull them together and consider the contribution they make to knowledge in the areas of family involvement and evaluation of interventions for children with autism. The relation of these findings to the theories of autism, described in Chapter 1, and the family social development theories, described in Chapter 2, will also be considered.

### 9.2 The theme of family involvement

It was clear from the literature review that over the past 40 years there has been a move away from a purely professional model of intervention delivery, to one that involves parents to at least some extent. Initially this move was fuelled by a realisation of the benefits for the child when the parents become involved, for example in terms of greater intensity of intervention delivery, when compared to interventions carried out solely by professional therapists. More recently though, a family-centred view has come to the fore, which focuses on the fact that involvement of parents will affect not only the child with autism, but also the parents themselves, and the family as a whole. It was also realised that, while there may be some benefits from involving the parents there are also likely to be drawbacks, and that for some families such involvement will be neither practical nor desirable.

A factor limiting research in the area of parental involvement was the lack of information on how many families participate directly in their child's intervention programme. A logical first step was therefore to establish how many parents are involved in interventions for their child with autism, and which interventions they use. This was carried out in the first study in this thesis, in relation to one large Scottish region. The study found that in around half of the families surveyed the children were currently involved in at least one intervention outwith school, and that parents of 13% of children were involved in interventions in which the parent typically took on the role of therapist to some degree. While therapist-based interventions have remained the most common over time, those which involved the parent as therapist seemed to have become increasingly common over recent years.

Although results of this study cannot necessarily be generalised to a wider geographical area, they do nonetheless suggest that the involvement of UK families in interventions outwith school is considerable, highlighting even further the need to conduct research into the resultant effects on families.

This thesis focused on one specific intervention, the Son-Rise Program, which was shown in Study 1 to be relatively common compared to other interventions, with numbers of families using it increasing. Studies 2 and 3 focused on families in the first year after initial training in this intervention. The aim was to establish data on a wide range of factors relating to implementation of the SRP, to create an initial picture of the experience of families using the approach, and to indicate fruitful avenues for future research.

The SRP was categorised in Study 1 as being a 'high parent involvement' intervention. Such a label seemed justified as Study 2 showed that, although parents tended not to use the intervention as intensively as it is often described in the literature, it was nevertheless used for an average of 20 hours per week, with parents personally working with their child for more than half of these. If the additional time that parents spend running the program, recruiting volunteers and so on, is also considered, this represents an enormous commitment by the parents.

What stood out from Studies 2 and 3 was the tremendous variation in the way in which families implemented this approach. For example, some families used the Program for only a few hours

each week, whereas others used it for more than sixty. Some parents had no volunteers assisting with their Program, whereas others had as many as nine. The children involved ranged from two years to nearly thirteen. Such variation meant that there were a large number of variables to take into account when examining the factors likely to relate to the effects of involvement on the family.

In terms of the effects on the family, the SRP can be summed up as making family life happier, but more difficult. Although drawbacks were prominent, the response to the questionnaire in Study 2 also showed that the majority of parents still using the program after a year felt that involvement in it had increased happiness in their family. Parents participating in the interviews in Study 3 described how much they enjoyed working with their child in the Son-Rise playroom. There is perhaps a tendency in research into intensive interventions to focus on the difficulties faced by the parents involved, as is the case in disability research more generally (Crocker, 2000). This bias is perhaps appropriate, arising from a desire to identify the most helpful ways of supporting families using such interventions, and to provide guidance for families considering the approaches. Nevertheless, the positive side of being involved in the SRP expressed by many of the families involved in these studies should not be disregarded.

Around half of the parents in the questionnaire study did note a number of drawbacks for family life, however. The most common of these was less time to spend with their spouse and other children. In Study 3 the mothers interviewed described some of the strategies they used in an attempt to minimise the disruption for the family. Exploring the efficacy of these strategies is a potentially viable area for future research, and one that is likely to be of value to the families using this approach. Another difficulty, raised in the interview study by several of the mothers, was the reality of the limited involvement of their husbands, compared with their vision of an intervention run jointly by the two parents. In some cases though it did seem that the lesser involvement of one parent was essential for the smooth running of the whole family unit.

The finding in study 1 of a possible trend towards parents funding interventions themselves, rather than using interventions funded by the local authority, meant that when exploring the experience of families using the SRP in Study 2, financial implications were a consideration. It was found that the majority of the families experienced at least slight financial difficulties as a

result of intervention involvement. The interviews in Study 3 indicated that the financial need for both parents to work sometimes limited the time that they could spend using the SRP. It may be that if, in the future, this intervention becomes increasingly funded by the local authority, as seems to have been the case with the Lovaas approach, parents may use the SRP even more intensively, with implications of greater effects on family life.

The final two studies in this thesis, Studies 4 and 5, examined changes in the mothers' use of the Son-Rise techniques over time, and relate more directly to the second theme, prerequisites for evaluation. However, consideration of these studies in relation to the first theme of effects on the family does indicate possible areas for future research. The whole family system is likely to influence how parents implement the techniques of the SRP and changes in this over time. This was indicated in Study 5 by Mrs. H's comments that having a large family had somewhat affected her ability to implement the Son-Rise techniques, because it meant that she had little free time to reflect on her use of the Program. Other ways in which the family system may affect SRP technique implementation include the impact of a stressful family life on the parents' ability to remain focused when they are in the Son-Rise Playroom. A final consideration is that if parents are having difficulty implementing the techniques correctly, this is likely to have an impact on their vision of themselves as an effective therapist for their child, emotions which may then affect their interactions with the rest of the family. There are then a number of ways in the future in which issues of technique implementation may be explored in relation to the family system.

### **9.3 The role of family systems theory in understanding effects of intervention involvement on the family**

In Chapter 2 family social development theories by Minuchin (1974) and Bronfenbrenner (1979) were introduced as a way of conceptualising the effects on the whole family when the parents take on the role of therapist.

Minuchin's family-systems theory predicts that anything that affects one person in the family, such as intervention involvement, will inevitably influence the whole family. It also views the family as operating via a series of subsystems, each involving two or three family members. Such subsystems are necessary for the smooth running of the family, but difficulties arise when subsystems become too close to, or too distant from each other, or when involvement in one

system prevents involvement in another. Bronfenbrenner's human ecology theory takes a wider focus and views the child as placed within a series of nested social systems, from immediate family to the society in which the family live.

To some extent these two theories provided a useful framework for understanding the effects on the family of intervention involvement. For example, in line with Minuchin's theory, it was found that the mothers did generally perceive their involvement in the SRP as affecting all of the family members, in terms of less time to spend with their spouse and other children, and in some cases an improved relationship with them as a result of learning about the Son-Rise philosophy of 'happiness is a choice'. The concept of subsystems was also supported, as well as the idea that such systems can be beneficial for effective family functioning. For example in Study 3 some of the mothers described how the fathers spent time with the other children in the family while they used the SRP with the child with autism. This meant that none of the children missed out on parental attention. However, as predicted by Minuchin's model, difficulties did arise when the subsystems became too close, such as when the other children were involved in working as therapists in the Son-Rise playroom, or when the subsystems became too distant, such as when the fathers decreased their involvement in the Program.

While Minuchin's model does not take account of the role of outside influences on effects on the family, Bronfenbrenner's theory fills this gap. As predicted by this model, a number of external factors did influence the way in which the family's SRP was run. For example aspects such as the availability of volunteers, the employment of both of the parents, the decisions regarding school attendance and, in some cases, the fundraising efforts of the wider community, all had an influence on the type of SRP that the parents provided for the child and the subsequent effects on the whole family.

To some extent then, these two theories did provide a useful way of conceptualising the way in which the SRP affects the whole family. The two are not competing theories, but fit rather well together; where the strengths of Minuchin's theory lies in its ability to predict the dynamic within the family, Bronfenbrenner's theory completes the picture by bringing in the role of external influences. Both also predict that any effects on the family are likely to change over time, as the family and the society in which they exist are constantly changing entities.

However, perhaps where these models fall down is that they lack the specificity to predict precise effects on the family and to explain how families deal with any difficulties which arise. For example, while Bronfenbrenner's model predicts that outside societal influences will play a role in determining the family's experience of using the SRP, it does not indicate precisely which external factors will have an effect, why factors will affect some families and not others, and whether the external factors are likely to have a positive or negative effect on the family. Minuchin's model is perhaps more precise in predicting which families are likely to be most affected by their involvement in the SRP, those in which there are difficulties with the subsystems being too close or too distant. However, this model still leaves a number of areas unexplained. For example, it does not really take account of the ways in which the family's methods of interaction prior to intervention use predict the effects on the family once they do begin the SRP, nor does it explain why some families manage to deal with negative effects and others do not. The question also remains as to how the same subsystem (such as the father spending time with the other children in the family) can at one and the same time be regarded as both positive, in that it means that the children get parental attention, and negative, in that it reduces the amount of time the father spends on the SRP.

In the period following the data analyses for this thesis another theoretical model was brought to the author's attention - McCubbin and Patterson's Double ABC-X model of stress (1982, 1983). This predicts that there will be an interaction between the primary stressor (A) – in this case involvement in the SRP – and family resource factors (B) such as coping strategies and social support, and the family's perception of the stressor (C). This interaction will result in the family adaptation outcome (X). This model does fit well with some of the findings of this thesis. For example, holding meetings for volunteers was found to be significantly related to positive family adaptation, indicated by a high level of happiness. Such meetings can be seen as providing social support (B). Positive family adaptation in terms of high levels of happiness and low stress levels was correlated with a perception that the program was very effective (C).

This model does then seem to provide a more solid framework in which to understand some of the effects on the family, and its strength lies in the fact that it not only takes account of the cause of stress but also of the differential effect produced by the way in which these sources of stress are perceived. Another advantage of this model is the way in which it takes account of changes over time as additional causes of stress emerge, new coping and support resources are acquired, and perceptions of the stressor change (Krauss, 1997). Presumably such a model could also be usefully broken down to the level of individual family members to explain how the differences in availability of social support and perceptions of stressors lead to differential adaptation in each family member. The model has recently proved itself to be a helpful way of conceptualising family effects in another intensive parent-run interventions, the Lovaas approach (Hastings & Johnson, 2000).

The greater specificity of this model would perhaps have made it a useful framework for understanding family adaptation within this thesis. However, it is not as helpful as Minuchin's theory in explaining the resultant relationships between each of the family members, and, unlike Bronfenbrenner's theory, it takes little account of the influence of external factors such as school and parental employment, except in their capacity to provide social support. Therefore a more complete picture of the effects on the family when the parents become involved in intensive interventions for their child with autism can perhaps be obtained in the future if these three models are applied in combination.

#### **9.4 The theme of prerequisites for evaluation**

The second theme examined throughout this thesis was the notion that although rigorous evaluation of a number of interventions for autism is much needed, the validity of such evaluations may be compromised if the research is designed in a way which is unrepresentative of how the intervention is used outwith the research environment.

A first obvious step was therefore to identify which interventions are current research priorities. This was carried out in the first study in this thesis, which identified speech and language therapy, music therapy, diet and the SRP as the most commonly used interventions at present. These findings indicate useful areas in which to focus research, although they are of course only representative of one region, and it may be that there are some regional differences.



The difficulty in identifying interventions which are research priorities is that while some interventions such as speech and language therapy may remain consistently popular, the use of other interventions may rise and fall. New interventions are constantly appearing and often become popular for a relatively short time. For example, in the time since the data for Study 1 has been collected, two new approaches to autism, secretin treatment and the Picture Exchange Communication System (PECS), have been used by families within the region. Such a rapid turnover of interventions makes identification of research priorities difficult. Perhaps more enduring research findings can be created by trying to extract general principles from intervention research, such as which specific features of an approach are important, and which child and family characteristics are associated with optimal intervention outcome. The feasibility of such 'second generation research' (Guralnick, 1997) is somewhat limited though because without a very large sample size only a very small number of characteristics can be adequately investigated within a single piece of research.

Another means of maximising the relevance of research is establishing which types of children and families are commonly involved in specific interventions, and how such interventions are typically used. This would allow research that is representative of use of the intervention in the 'real world' to take precedence. Such work was carried out in relation to the SRP in Studies 2 and 3. The findings of these studies emphasised that it is not safe to assume that an intervention is used as it is commonly described in the literature. Families adapted the Program to their own child and family circumstances - in some cases using the Program less intensively than it is often described, in others using it in combination with school and additional interventions, and in some cases modifying specific aspects of the techniques. Such modifications are positive, in that they show that families do not feel the need to rigidly apply the Program intensively and exclusively when this may be neither practical nor appropriate for them.

It is encouraging to find that in the time since the research in this thesis was undertaken, similar demographic work has been undertaken in relation to use of the Lovaas approach in the UK (Mudford *et al*, 2001). As with the SRP findings in this thesis, Mudford *et al* report wide variation in the way in which the Lovaas approach was implemented. In none of the 75 families

surveyed was the approach being implemented in a manner totally consistent with the methodology of the Lovaas (1987) evaluation study.

The finding of great variation in intervention use in Studies 2 and 3 has two implications for research into the SRP, and into interventions in general. Firstly, it is not advisable to base evaluation designs on assumptions of how an intervention is used: if in practice the intervention tends to be used very differently, then the findings of such an evaluation would be of little use. Secondly, because of the wide variation in who uses an intervention and how it is used, it should be made clear in any evaluation that the findings of the research are limited in the extent to which they can be generalised. While evaluation studies may show positive outcomes, these will only be in relation to specific children and specific families implementing the intervention in a specific way. Implementing the intervention in a different way or with a different type of child may produce an alternative outcome.

Despite the variation in use of the SRP found in Study 2 it was nevertheless possible to form a profile of typical children involved and typical patterns of use, a profile upon which any future evaluation design could be based. However, such an evaluation would need to be carried out in the near future because it is possible that such a profile may change over time. Any number of factors may contribute to such a change. For example, alterations in LEA-provided provision may influence the number of hours per week for which parents use alternative approaches like the SRP, and media attention on positive outcomes in specific families may encourage more families with similar characteristics to begin using the approach. Although the validity of the findings of Study 2 are, at least to some extent, time-limited they do nevertheless fill a previous gap in the literature by providing a framework for future evaluation design.

Another finding from Studies 2 and 3 that has important implications for the design of future evaluation studies was that a large proportion of families use the SRP in combination with school and other interventions. This would make it difficult to attribute any behavioural change in the child found during an evaluation specifically to the SRP. It is difficult to find a way around this problem in evaluation design; indeed such constraints of real life often limit how 'experimentally pristine' one can be in evaluation research (Kazdin & Weisz, 1998). As described in Chapter 5, the ethics of asking parents involved in evaluation research not to

become involved in any other interventions is highly questionable. In terms of school attendance it may be possible to have a group who attended school in addition to the SRP and a group who did not. However, it would also be necessary to match the number of hours SRP provided to each group, which would mean that the non-school group would be left with no educational or therapeutic input while the other group attended school, again not a satisfactory solution. Another possibility would be to collect data relating to developmental change in the children involved in the SRP very frequently, so that if the parents then began additional interventions at some point, the effects of this on the rate of developmental progress in the child could be measured. However, this assumes that additional interventions would have an immediate rather than a delayed effect on the child's progress and that progress within the SRP occurs at a constant rate; this seems unlikely. In short, the problem of concurrent intervention use in families involved in evaluation studies is one that is not easily avoided, and the limitations which it places on the strength of findings of any evaluation study are perhaps inevitable.

The findings of Studies 2 and 3 raised the issue of another potential threat to the validity and reliability of any future evaluation study into the SRP: the possibility that parents may not be applying the SRP as it has been described and taught. In Study 2 it was found that around half of the families involved did not make use of the support services provided by the Option Institute. Although for some families this was because they felt that they did not require assistance because their Program was going well, for others it was due to the prohibitive cost of the services. This raised the possibility that some parents may have had difficulty in maintaining a high degree of intervention fidelity throughout their use of the Program. In Study 3 several of the mothers described ways in which they altered their use of the SRP to help tailor it to their own style and their own child's abilities. This highlighted the fact that, even if situations where parents have received the training necessary to implement the intervention exactly as it was taught, they may not wish to do so. While a high degree of intervention fidelity is necessary in evaluation research, it seems unlikely that it will always be best for the child and the family.

Studies 4 and 5 explored the issue of intervention fidelity and changes in the use of Son-Rise techniques over time. Study 4 found an initially high level of intervention fidelity in most of the 5 families studied, using video analysis of therapy sessions. While there was some change over time in technique implementation, this was limited to only some families and some individual

techniques. The interviews in Study 5 confirmed that the mothers themselves also felt that there had been some change in their implementation of the Program over time. In some cases they felt that this was due to attending training and being made aware that they could modify their previous method of technique implementation. In other cases, the mothers had changed their emphasis on the various techniques in order to adapt the Program to developmental changes that they had perceived in their child.

Although issues of intervention fidelity and changes in technique implementation over time did not relate to all of the families, the findings of Study 4 did indicate that these issues do, to some extent, constitute a potential threat to the validity and reliability of future evaluation studies. However, the most important points raised in these studies for evaluation research are (i) the difficulty of establishing ways of measuring fidelity in child-led unstructured interventions such as the SRP, (ii) the problem of knowing when changes in technique use over time are within the parameters of the intervention protocol and when they lead to a decrease in fidelity which would be unacceptable in an evaluation study.

This clearly presents a challenge for the future. Some measures can be readily applied in establishing intervention fidelity, such as looking at how often techniques are used which go against the Son-Rise philosophy of respect for the child's choices. For many other techniques though, it became clear from Studies 4 and 5 that as there was no set frequency with which they should be used in the SRP, it was sometimes impossible to tell when they were been used too rarely and when too frequently. It seems likely that measuring the use of these techniques in relation to the child's behaviour will be the most productive way forward, for example looking at which proportion of the child's stereotypical behaviour the adult imitates.

While Study 4 indicated only limited relations between the mothers' use of techniques and the child's behaviour, the interviews in Study 5 suggested more extensive links. It may be that in future video analysis studies, the methods of establishing links utilised in Study 4 can be built on, for example by using models based on combinations of the child's behaviour, rather than individual aspects, and by including additional aspects of the child's behaviour. It may also be that examining the relationship between the child's behaviour and the mother's use of techniques

on a moment-to-moment basis within a single session will produce the most accurate measures of intervention fidelity.

## **9.5 Linking theories of autism with intervention research and practice**

Within the field of interventions for autism there is a need to forge stronger links between theory and practice. The benefits of doing so are bi-directional: theories of autism provide an understanding of how and why interventions work, while research into intervention practice may provide an indication of the accuracy of particular theoretical positions (Jordan *et al*, 1995; Rapport, 2001). Good lines of communication between those concerned with theories of autism and those working on a practical level are also essential to ensure that recommendations for intervention are not only theoretically strong but also realistic and feasible. For example, while theories of plasticity of functioning in the brain of the young child point to the advantage of very intensive intervention while the child is young, to produce a feasible approach this must be combined with the practical knowledge of the possible detrimental effects on the parents if they provide such an intensive intervention.

In terms of the connections between theory and practice within this thesis, the theories of family social development theory proved useful in helping to understand one specific aspect of the SRP – the effects on the family of involvement. However, more general links between the theories of neurology and psychology presented in Chapter 1 and the SRP are difficult to find.

Although the SRP is not itself derived from any particular theoretical approach, the fact that its primary focus is on the interpersonal relationship between the adult and child does mean that it sits well with Hobson's affective-deficit theory, as described in Chapter 1. Like many of the other child-led interventions it also uses techniques which stem from theories of mother-infant interaction, as described in Chapter 4. Such theories are helpful in providing a general understanding of why the SRP may produce behavioural change in the child with autism, but it does not provide specific and detailed predictions about the mechanisms by which this occurs. In addition because this thesis, as with all research into interventions, was practically rather than theoretically focused, it is difficult to find ways in which the findings of the research feedback into further development of these theories.

Although then there are theories that bear on the SRP, overall it is difficult to place this research within a strong theoretical framework. The main reason for this is the lack of existing literature connecting theory and practice. This difficulty is not specific to the SRP. It has been noted that within autism and developmental difficulties more generally, connections between theory and practice are difficult to find (Jordan *et al*, 1995; Kazdin, 1999; Rapport, 2001).

Although it is appropriate for studies into interventions to have a primarily practical viewpoint, such research would nonetheless be enriched if a theoretical perspective were incorporated. It is therefore important in the future for stronger links to be forged between theories such as Hobson's affective-deficit theory and research into child-led approaches such as the SRP. Doing so will decrease the distance between theory and intervention research, and thus provide greater assistance in either supporting or refuting the theory (Rapport, 2001). Such a task is likely to prove difficult however, not least because Hobson's theory deals with the wide-ranging area of intersubjective understanding, from which it perhaps more difficult to derive specific testable predictions than it is for other theories, such as theory of mind or central coherence theory.

Sigman and Capps' theory that the development of early socio-cognitive skills (such as joint attention and social referencing) are vital for the child's later functioning (e.g. language development) perhaps offers a possible way of better connecting theories of autism with research into interventions. The development of early skills in children involved in the SRP could be compared both against children with autism involved in other interventions, and those not involved in any intervention. The children's functioning in later life in language and social understanding could then be compared to ascertain whether there did indeed seem to be links to these early skills, and whether the intervention used had an effect on development. Findings from such research could establish the validity of Sigman and Capp's theory, and perhaps also provide a framework in which to understand whether, and how, the SRP techniques bring about developmental change in the child. There would of course be problems with such research, for example the difficulty of concurrent therapy involvement previously described in this chapter (pxxx). However, the theory of Sigman and Capps does perhaps offer the most clearly defined and testable predictions in relation to the SRP.

## 9.6 Implications for families and professionals

Throughout the five studies in this thesis there were a number of implications from findings which may be helpful for families considering using this approach, for professionals supporting those families, and for service providers more generally. Of course these implications are inevitably based, to some extent, on generalisations of the findings of these studies and not therefore relevant for every family considering this approach. Nevertheless, the frequency with which some of these issues were raised across several of the studies indicates that they may be important considerations for many of those involved with the SRP and to some extent with interventions for children with autism more generally.

Perhaps the most important of these relates to the large proportion of children across the studies who attended school in addition to being involved in the SRP. Many parents continued their child's education because they considered school to be a beneficial environment, not because they were unable to run a full-time SRP and had no option but to send their child to school. This is a very positive finding. It is important though that the compatibility of the two environments is maximised. Good communication and a degree of flexibility on the part of both teachers and parents seemed important in this respect. This was highlighted by some of the specific strategies discussed by parents in Study 3, such as a two-way sharing of information between the school and home about developmental goals for the child, and parents offering the school information on the Son-Rise techniques. It is likely that the former strategy is already the norm, even in cases where the child is not involved in an intervention outside school (Jones, Meldrum, & Newson, 1995), although the type and level of input that parents have in this process may change when the parents take on the role of therapist in an intervention such as SRP.

The interviews in Study 3 indicated that a lack of conflict between school and Son-Rise may be more likely with younger children, although the limited number of children from different age groups involved in this study means that further research is required to confirm whether this is always the case. In the future further research should also be conducted into both the efficacy of strategies employed to maximise compatibility between the two learning environments, and the identification of child and school characteristics that are related to a high degree of compatibility.

The implications for the educational system are no less important in situations where the family decides to discontinue school attendance in order to run a full-time SRP at home. Comments made by one mother in Study 3 indicated the importance of keeping the child's school place open for a period in such situations. This arrangement is advisable as it provides continuity for the child if, and when, they do return to school; it also eases pressure on the parents by offering a 'safety net' if the Program does not work out as well as expected. Families in this position should also consider whether withdrawing the child from school will mean that the child loses access to related services, as was the case with one family in Study 3.

In addition to considerations relating to school attendance, a number of other issues were raised in Studies 2 and 3. One of these was that in Study 2 it was found that the majority of families initially accessed information about the SRP through the media. Given the power of television and newspapers in determining the interventions which parents go on to use, it is important that reports about interventions such as the SRP are well balanced, emphasising the difficulties which some families involved in them face, as well as the 'success stories'. One way of doing this would be to feature families who had been using the intervention for some time, so that initial enthusiasm for the intervention is mixed with the reality of using the Program over a long period of time. This would allow longer-term effects on the child and family of being involved in the SRP to be considered.

Despite the high degree of intensity with which some parents used the approach, the type of SRP used by parents was still significantly less intensive than they had initially envisaged, both in terms of their own input and the input of volunteers. Although high expectations by parents beginning this approach are perhaps essential to create the momentum to run the Program, it is important that they do not feel that they have failed in any respect if they do have difficulty in recruiting volunteers or in working with their child as intensively as they had hoped. While success stories of families who have used this approach with a very positive outcome do provide inspiration and motivation for other families, there is the risk that these create a 'gold standard' of service delivery against which parents compare themselves and their efforts in a negative fashion. It is important that professionals supporting families using this approach discourage such comparisons being drawn.



For many families the number of volunteers that they are able to recruit may be the factor limiting the intensity of Program which they are able to create, something which families considering the approach should also bear in mind. As noted in Chapter 5 a potential solution would be for universities to provide course credits for volunteer work, although this would not help families in rural areas, who presumably have the most difficulty finding volunteers.

Those considering using the approach should also note the potential drawbacks for family life which were noted by a number of families in Studies 2 and 3, such as a resultant lack of time to spend with other children in the family. Such drawbacks may not be severe in effect but parents may benefit from considering how to monitor and minimise such difficulties. Such drawbacks are not, of course, inevitable and there may also be benefits for the family, including increased happiness, an improved relationship with the child with autism, and enjoyment gained from spending time with the child using the techniques of the Program. In Study 2 a positive family experience of involvement in terms of low stress levels and increased happiness was related to a high level of perceived efficacy of the SRP for the child. While this suggests a positive family outcome when the Program is perceived as running well, Hastings and Johnson (2000) note that professionals supporting families using such interventions must be aware that such findings do suggest that families may be at risk if they begin to have serious doubts about the programs with which they are involved.

In relation to efficacy, findings from Study 2 indicated that although many parents noted constant progress, in most cases this was minor rather than major, and in some cases progress was perceived as occurring in spurts rather than constantly. As noted in Chapter 5, it is therefore important for families embarking on the Program to be prepared for periods of little or no obvious developmental change in the child. However, even minor progress may make a substantial difference to family life, and if this represents an improvement on the rate of progress by the child prior to the SRP, this will not then be a source of disappointment.

Within the interviews in Study 5, as with Studies 2 and 3, the importance of the ongoing training provided by the Option Institute was highlighted. In Studies 2 and 3 relationships were found between attending the advanced training and an increase in confidence and motivation, and in Study 5 parents were largely of the opinion that the Program could not be implemented

effectively over a long period of time without making use of the support services. Despite this only limited uptake of support services was found in Study 2.

There are a number of ways in which uptake of support services could be potentially increased. An obvious one, indicated by the comments made by parents throughout the study, is a decrease in the cost of these services and an increase in the number of Son-Rise trained staff based in the UK. Several parents noted that lack of time was another reason for not making use of the services, and one of the mothers involved in Studies 4 and 5 suggested that this could be circumvented to some extent if the Option Institute took on more of the organisation involved in using the services, for which parents are currently responsible. For example, if the Option Institute offered a package of regular support services, arranged times for phonecalls or video feedback to take place, and took the responsibility for contacting the families on each occasion, this would save families the inconvenience of having to arrange use of the services on each separate occasion; something which some parents found difficult given the demands of a busy family life and the added complication of the time difference between the UK and the States when using the support phonecall service.

Even with such improvements though, parents will not make use of these services if they do not see the need, and it is relevant here that some of the parents in Study 5 noted that it was only with hindsight that they realised the advantage of making good use of the support services from the beginning of their SRP. This is something which families considering using the approach should perhaps bear in mind. Even if the support services offered by the Option Institute are not used it may be that informal support such as feedback from a spouse or group meetings with volunteers will be beneficial.

It is important to reiterate that each of the implications for families discussed here will not be relevant for every single family considering using the approach. However, in this thesis, all were consistently found to be important issues for many of the families currently using the SRP, and as such are likely to be relevant for a substantial proportion of those using it in the future.

## 9.7 Limitations and implications for future research

Specific limitations related to each study were discussed in the relevant chapters. The aim of this section is to explore more general limitations that were common across the thesis, and to explore ways in which these could be overcome in any future study. In addition, ways in which the findings of these studies could be further expanded on in future research will be considered.

Perhaps the most salient point is the relatively small sample size in Studies 3, 4, and 5. Within the timescale of this thesis a larger sample size would have been impractical in terms of the time required for data collection and analysis, particularly in relation to the video analysis in Study 4 which involved a lengthy categorisation and analysis procedure. Given the criticisms of previous intervention research into family effects and intervention fidelity with data collection occurring at only a single time-point, it seemed that the advantages of conducting data collection in Studies 3 and 4 on a longitudinal basis outweighed the disadvantages of the reduction in sample size that this necessitated.

Although the extent to which findings of studies with small sample sizes can be generalised is clearly limited, throughout the thesis rigorous sampling methods were employed and this strengthens, to some extent, the claims that can be made (Platt, 1988). For example, within Study 3 a stratified purposeful sampling method was used so that the interview sample was proportionally representative of key characteristics of the much larger UK-wide sample involved in Study 2. Study 3 involved families from across Scotland, and covered a wide spectrum of intervention use, from those who used the Program intensively, to those who eventually chose not to implement the Program. In Study 4 the families involved were all of the families within the region who had attended the Son-Rise Start-Up training. There were thus no issues of self-selection, or biased sampling: participants were simply the most representative sample that could be found within the geographical parameters.

The small sample size should not detract from the valuable results that the studies produced. Studies 3 and 5 provided triangulation for the studies which had been conducted prior to them. They also allowed expansion of the previous findings, and helped to indicate possible explanations for some of these. All of the studies raised issues and produced findings which can now be further explored in larger scale studies.

Another potential criticism of the research conducted within this thesis may be the large number of topics which were covered within Study 2, inevitably limiting, to some extent, the depth with which any single topic could be covered. However, although many topics were addressed, this seemed to be the most advisable route to take given that the lack of prior research into the SRP and the consequent lack of information in a number of important areas. By covering a number of topics in Study 2 it was possible to create a global picture of patterns of use and of the experience of families using the SRP. Through this it was possible to identify the most salient topics which could then be addressed in greater depth through the interviews in Study 3, and which can now be explored through further studies in the future. Focusing on only a single topic relating to the SRP before establishing a representative picture of typical use and identifying the most important issues for families using the approach would have been both premature and likely to have produced uninterpretable findings.

One further issue which may also be conceived of as a limitation is the fact that throughout the studies it was primarily the mothers of the families who were involved. However, in interventions like the SRP it is normally the case that mothers are the primary care providers (Tissot, 1999). Involving mainly mothers in the studies thus helped to increase the generalisability of the findings. This is not to imply that mothers are the only family members involved in the SRP, nor that the perspectives of others involved in the intervention, such as fathers, siblings and volunteers, are unimportant. However, as the studies in this thesis represent the first known investigations into family effects, it seemed important that initially these findings came from the perspective of those who were in most cases primarily responsible for running the interventions – the mothers.

In the future it will be informative to explore some of the findings found in these studies from the perspective of other family members and those involved as volunteers in the Program. For example, many parents in Studies 2 and 3 felt that using the SRP meant that they had less time to spend with their other children. In future studies it would be interesting to find out whether the other children in the family also felt this was the case, and what their overall experience was of their parents being involved in this approach. In the studies in this thesis parents also noted the difficulty of recruiting volunteers. Many questions pertaining to volunteers remain to be

investigated. For example, why do those who volunteer on an SRP make the decision to do so, and what is their experience of being involved with the Program? It would also be helpful to explore the reasons that discourage people from volunteering for families or lead to drop out.

In Study 3 several of the mothers commented that they wished that their husbands were more involved in the running of their Program and viewed it as more of a joint venture. It would be interesting in the future to gather views from the husbands' perspective on how they conceived their role within the SRP, and on the effects that they felt it had on the family dynamic.

In relation to the changes in technique implementation over time found in Studies 4 and 5, this could be investigated further in the future by examining whether fathers and volunteers working on the Program show similar patterns of changes over time, and whether ongoing training produces similar changes in all of those working with any one child. Studies 4 and 5 could also be further extended by replication with a larger sample of mothers and more frequent data points to explore in greater detail some of the trends identified within this thesis. It is important though, as discussed in Chapter 7, to make sure that any increase in frequency of filming does not place an unreasonable burden on the families involved in the study.

This thesis continued in the tradition of more recent research into interventions for autism, moving away from considering only the effects on the child with autism to looking at the effects on the wider family when parents take on the role of therapist. It may be possible for future research in this area to take this a stage further, and come full circle by considering the influence that these family effects in turn have on the child with autism. For example, it could be examined whether the feelings the siblings have about the SRP being used then impacts on their interactions with the child with autism outwith the Son-Rise playroom. Such effects are predicted by Minuchin's family systems approach, suggesting that the family is an interactional unit and factors which affect one member will in turn affect the rest of the family.

This thesis followed some families' use of the SRP over the course of a year, but many families continued to use the Program after the end of the period of study. It would be informative in the future to interview the mothers again after the end of their SRP, to explore issues such as whether they felt any positive effects on themselves, in terms of a more positive outlook and an

improved relationship with their child, had been maintained. It would also be interesting to see whether they felt that the benefits to the child of being involved in the Program had been maintained, and whether they experienced any difficulties involved in coming to the end of the Program, for example in relation to the child returning to school in cases where the Program had been used on a full-time basis.

A number of ways in which the findings of this thesis can be extended have been outlined above. These are all important areas of potential research within the SRP but it is clear that a well-designed evaluation of the SRP is the most urgently required piece of research that should take place. It is hoped that the profile of typical users and patterns of use provided in Studies 2 and 3 will prove helpful in this respect, and that the issues of intervention fidelity raised in Studies 4 and 5 will also be taken into consideration in the design of any such study.

## **9.8 Overview**

This thesis set out to explore two main themes – the effects on the family of SRP involvement and the prerequisites for evaluations of this particular intervention. Through a series of five inter-linked studies utilising both quantitative and qualitative methodologies, it was possible to produce an initial picture of how this intervention is currently used in the UK, and findings which contribute to knowledge within each of the two themes. It is hoped that these findings will prove helpful for those concerned with evaluation of the SRP in the future, and for parents and professionals involved with this intervention.

There are a number of ways in which this research could be built on in the future, chiefly through replication with larger participant groups and examination of the issues from the perspectives of others involved in the SRP: fathers, siblings and volunteers. Forging stronger links between research into this approach and relevant theoretical work is also likely to prove mutually beneficial for both theory and intervention development. Despite the extensive work that must still be done, it is hoped that the research in this thesis has made a contribution to understanding the experience of families involved in the SRP, and has clarified some of the issues involved in evaluation of this approach.

## BIBLIOGRAPHY

- Abidin, R. R. (1986). *Parenting Stress Index*. Los Angeles: Pediatric Psychology Press. Cited in Birnbrauer & Leach (1993).
- Adams, A. (1993, 28th September). Coaxed from a shut-away existence. *The Independent*.
- Akerley, M. S. (1984). Developmental changes in families with autistic children. In E. Schopler (Ed.), *Effects of Autism on the Family*. New York & London: Plenum Press.
- Alvin, J. (1978). *Music therapy for the Autistic Child*. London: OUP.
- Alvin, J., & Warwick, A. (1991). *Music Therapy for the Autistic Child*. Oxford: Oxford University Press.
- Aman, M. G., Van Bourgondien, M. E., Wolford, P. L., & Sarpahre, G. (1995). Psychotropic and anticonvulsant drugs in subjects with autism: Prevalence and patterns of use. *Journal of the American Academy of Child and Adolescent Psychiatry*, 34(12), 1672-1681.
- Anastasi, A., & Urbina, S. (1997). *Psychological Testing* (7th ed.). Upper Saddle River, NJ: Prentice-Hall Inc.
- Anderson, S. R., Avery, D. L., DiPietro, E. K., Edwards, G. L., & Christian, W. P. (1987). Intensive home-based early intervention with autistic children. *Education and Treatment of Children*, 10(4), 352-366.
- Angell, R. (1993). A parent's perspective on the preschool years. In E. Schopler & M. E. Van Bourgondien & M. M. Bristol (Eds.), *Preschool Issues in Autism*. New York & London: Plenum Press.
- Archer, M. (1997). Welcome to my world. *Special Children*, 106, 21-23.
- Armstrong, K. J., Ehrhardt, K. E., Cool, R. T., & Poling, A. (1997). Social validity and treatment integrity data: reporting in articles published in the Journal of Developmental and Physical Disabilities, 1992-1995. *Journal of Developmental and Physical Disabilities*, 9(4), 359-367.
- Atherton, J. (1997). Physiotherapy approach for people with autism. In Approaches to Autism. London: National Autistic Society.
- Atkeson, B. M., & Forehand, R. (1978). Parent behavioural training for problem children: an examination of studies using multiple outcome measures. *Journal of Abnormal Child Psychology*, 6(4), 449-460.
- Autism Scotland. (1997). *Autism: The Way Forward*. Report of conference held at Strathclyde University.
- Bailey, A., Le Couteur, A., Gottesman, I., Bolton, P., Simonoff, E., Yuzda, E., & Rutter, M. (1995). Autism as a strongly genetic disorder: evidence from a British twin study. *Psychological Medicine*, 25, 63-78.
- Bailey, A., Phillips, W., & Rutter, M. (1996). Autism: Towards an integration of clinical, genetic, neuropsychological, and neurobiological perspectives. *Journal of Child Psychology and Psychiatry*, 37(1), 89-126.
- Bakeman, R., & Gottman, J. M. (1986). *Observing Interaction; An Introduction to Sequential Analysis*. Cambridge: CUP.
- Baron-Cohen, S. (1987). Autism and symbolic play. *British Journal of Developmental Psychology*, 5, 139-148.
- Baron-Cohen, S. (1989a). Perceptual role taking and protodeclarative pointing in autism. *British Journal of Developmental Psychology*, 7, 113-127.
- Baron-Cohen, S. (1989b). The autistic child's theory of mind: a case of specific developmental delay. *Journal of Child Psychology and Psychiatry*, 30, 285-298.
- Baron-Cohen, S. (1995). *Mindblindness: An Essay on Autism and Theory of Mind*. Cambridge, Mass.: MIT Press.
- Baron-Cohen, S., Allen, J., & Gillberg, C. (1992). Can autism be detected at 18 months? The needle, the haystack and the CHAT. *British Journal of Psychiatry*, 161, 839-843.
- Baron-Cohen, S., Bolton, P., Wheelwright, S., Scahill, V., Short, L., Mead, G., & Smith, A. (1997b). Does autism occur more often in families of physicists, engineers, and mathematicians? *Autism*, 2(3), 296-301.
- Baron-Cohen, S., Jolliffe, T., Mortimore, C., & Robertson, M. (1997a). Another advanced test of theory of mind: evidence from very high functioning adults with autism or Asperger syndrome. *Journal of Child Psychology and Psychiatry*, 38(7), 813-822.
- Baron-Cohen, S., Leslie, A. M., & Frith, U. (1985). Does the autistic child have a "theory of mind"? *Cognition*, 21, 37-46.
- Baron-Cohen, S., Leslie, A. M., & Frith, U. (1986). Mechanical, behavioural and intentional understanding of picture stories in autistic children. *British Journal of Developmental Psychology*, 4, 113-125.

- Baron-Cohen, S., O' Riordan, M., Stone, V., Jones, R., & Plaisted, K. (1999). Recognition of faux pas by normally developing children and children with Asperger syndrome or high-functioning autism. *Journal of Autism and Developmental Disorders*, 29(5), 407-417.
- Barrett, M. (1995). Practical and ethical issues in planning research. In G. M. Breakwell & S. Hammond & C. Fife-Schaw (Eds.), *Research Methods in Psychology*. London: Sage.
- Bauman, M. L., & Kemper, T. L. (1994). *Neurobiology of Autism*. Baltimore, MD.: Johns Hopkins University Press.
- Bell, J. (1999). *Doing Your Research Project*. Buckingham & Philadelphia: OUP.
- Berkowitz, B. P., & Graziano, A. M. (1972). Training parents as behavior therapists: a review. *Behaviour Research and Therapy*, 10, 297-317.
- Bernard, S., Enayati, A., Redwood, L., Roger, H., & Binstock, T. (2001). Autism: a novel form of mercury poisoning. *Medical Hypotheses*, 56(4), 462-471.
- Bettelheim, B. (1967). *The Empty Fortress: Infantile Autism and the Birth of the Self*. New York & London: The Free Press - MacMillan Publishers.
- Birnbrauer, J. S., & Leach, D. J. (1993). The Murdoch early intervention program after two years. *Behaviour Change*, 10(2), 63-74.
- Borg, W. R., & Gall, M. D. (1989). *Educational Research: An Introduction* (5th ed.). New York & London: Longman.
- Bowler, D. M. (1992). 'Theory of mind' in Asperger's syndrome. *Journal of Child Psychology and Psychiatry*, 33, 877-893.
- Briskman, J., Happe, F. G. E., & Frith, U. (2001). Exploring the cognitive phenotype of autism: weak "central coherence" in parents and siblings of children with autism II. real-life skills and preferences. *Journal of Child Psychology and Psychiatry*, 42(3), 309-316.
- Bristol, M. M. (1979). *Maternal coping with autistic children: the effect of child characteristics and interpersonal support*. Unpublished doctoral dissertation, University of North Carolina at Chapel Hill. Cited in Morgan (1988).
- Bristol, M. M. (1984). Family resources and successful adaptation to autistic children. In E. Schopler (Ed.), *Effects of Autism on the Family*. New York & London: Plenum Press.
- Bristol, M. M. (1985). Designing programs for young developmentally disabled children: A family systems approach to autism. *Remedial and Special Education*, 6, 46-53.
- Bristol, M. M., Cohen, D. J., Costello, E. J., Denckla, M., Eckberg, T. J., Kallen, R., Kraemer, H. C., Lord, C., Maurer, R., McIlvane, W. J., Minshew, N., Sigman, M., & Spence, M. A. (1996). State of the science in autism: report to the National Institutes of Health. *Journal of Autism and Developmental Disorders*, 26(2), 121-154.
- British Psychological Society. (2000). *Code of Conduct, Ethical Principles and Guidelines*. Leicester: BPS. Available: <http://www.bps.org.uk>
- Bronfenbrenner, U. (1979). *The Ecology of Human Development: Experiments by Nature and Design*. Cambridge, MA.: Harvard University Press.
- Bronfenbrenner, U. (1986). Ecology of the family as a context for human development: Research perspectives. *Developmental Psychology*, 22(6), 723-742.
- Bryman, A., & Burgess, R. G. (Eds.). (1994). *Analyzing Qualitative Data*. London & New York: Routledge.
- Bryson, S. E., Clark, B. S., & Smith, I. M. (1988). First report of a Canadian epidemiological study of autistic syndromes. *Journal of Child Psychology and Psychiatry*, 29, 433-445.
- Buhagiar, N. (1999). *Therapists experience of treating pre-school autistic children*, [website]. Autism '99 Online Conference. Available: <http://www.autism99.org> [1999].
- Burford, B. (1991). Communicating through movement and posture. In W. I. Fraser & R. C. MacGillivray & A. M. Green (Eds.), *Hallas' Caring for People With Mental Handicaps*. Oxford: Butterworth Heinemann.
- Burford, B. (1993). Helping with communication through movement. In E. Shanley & T. A. Starrs (Eds.), *Learning Disabilities: A Handbook of Care*. Edinburgh: Churchill-Livingstone.
- Cameron, R. J. (1982). *Working Together: Portage in the UK*. Windsor: NFER-Nelson.
- Campbell, M., Schopler, E., Cueva, J. E., & Hallin, A. (1996). Treatment of autistic disorder. *Journal of the American Academy of Child and Adolescent Psychiatry*, 35(2), 134-143.
- Campion, J. (1985). *The Child in Context: Family-Systems Theory in Educational Psychology*. London, New York: Methuen.



- Cantwell, D. P., & Baker, L. (1984). Research concerning families of children with autism. In E. Schopler (Ed.), *Effects of Autism on the Family*. New York & London: Plenum Press.
- Cantwell, D. P., Baker, L., & Rutter, M. (1978). Family factors. In M. Rutter & E. Schopler (Eds.), *Autism: A Reappraisal of Concepts and Treatments*. New York & London: Plenum Press.
- Capps, L., Sigman, M., & Mundy, P. (1994). Attachment security in children with autism. *Development and Psychopathology*, 6, 249-261.
- Caro, T. M., Roper, R., Young, M., & Dank, G. R. (1979). Inter-observer reliability. *Behavior*, 69, 303-315.
- Case-Smith, J., & Bryan, T. (1999). The effects of occupational therapy with sensory integration emphasis on preschool-age children with autism. *American Journal of Occupational Therapy*, 53(5), 489-497.
- Case-Smith, J., & Miller, H. (1999). Occupational therapy with children with pervasive developmental disorders. *American Journal of Occupational Therapy*, 53(5), 506-513.
- Christie, P., & Wimpory, D. (1986). Recent research into the development of communicative competence and its implication for the teaching of autistic children. *Communication*, 20, 4-7.
- Clements, J. (1985). Training parents of mentally handicapped children. *Newsletter of the ACPP*, 7, 2-9.
- Cohen, D. J., Manion, L., & Morrison, K. (2000). *Research Methods in Education*. (5th ed.) London & New York: Routledge.
- Cohen, S. (1998). *Targeting Autism: What We Know, Don't Know, and Can Do to Help Young Children with Autism and Related Disorders*. Berkeley: University of California Press.
- Coolican, H. (1999). *Research Methods and Statistics in Psychology* (3rd ed.). London: Hodder & Stoughton.
- Cook, E. H. (1990). Autism: review of neurochemical investigation. *Synapse*, 6, 292-308.
- Courchesne, E. (1989). Neuroanatomical subsystems involved in infantile autism. The implications of cerebellar abnormalities. In G. Dawson (Ed.), *Autism: Nature, Diagnosis and Treatment*. New York: Guilford Press.
- Courchesne, E., Yeung-Courchesne, R., Press, G. A., Hesselink, J. R., & Jernigan, T. L. (1988). Hypoplasia of verbellar vermal lobules VI and VII in autism. *New England Journal of Medicine*, 318, 1349-1354.
- Crocker, A. C. (2000). Introduction: the happiness in all our lives. *American Journal of Mental Retardation*, 105(5), 319-325.
- Crosbie, J. (1993). Interrupted time series analysis with brief single subject data. *Journal of Consulting and Clinical Psychology*, 61(6), 966-974.
- Cummins, R. A. (1988). *The Neurologically Impaired Child: Doman-Delacato Techniques Reappraised*. London: Croom Helm.
- Cutler, B. C., & Kozloff, M. A. (1987). Living with autism: effects on families and family needs. In D. J. Cohen & A. M. Donnellan & R. Paul (Eds.), *Handbook of Autism and Pervasive Developmental Disorders*. New York: John Wiley & Sons.
- Dawson, G., & Adams, A. (1984). Imitation and social responsiveness in autistic children. *Journal of Abnormal Child Psychology*, 12(2), 209-225.
- Dawson, G., & Galpert, L. (1990). Mothers' use of imitative play for facilitating social responsiveness and toy play in young autistic children. *Development and Psychopathology*, 2, 151-162.
- Dawson, G., & Lewy, A. (1989). Arousal, attention and the socioemotional impairment of individuals with autism. In G. Dawson (Ed.), *Autism: Nature, Diagnosis and Treatment*. New York & London: Guilford Press.
- Dawson, G., & Osterling, J. (1997). Early intervention in autism. In M. J. Guralnick (Ed.), *The Effectiveness of Early Intervention*. Baltimore: Paul H. Brookes.
- Degangi, G. A., Wietlisbach, S., Goodin, M., & Scheiner, N. (1993). A comparison of structured sensorimotor therapy and child-centered activity in the treatment of preschool children with sensorimotor problems. *American Journal of Occupational Therapy*, 47(9), 777-786.
- DeMyer, M. K. (1979). *Parents and Children in Autism*. New York: John Wiley.
- Detrich, R. (1999). Increasing treatment fidelity by matching interventions to contextual variables within the educational setting. *School Psychology Review*, 28(4), 608-620.
- DfEE. (1997). *Excellence for all Children: Meeting Special Educational Needs*. London.
- Dryden, W. (1984). *Individual Therapy in Britain*. London: Harper & Row.
- Dunham, P. J., Dunham, F., & Curwin, A. (1993). Joint-attentional states and lexical acquisition at 18 months. *Developmental Psychology*, 29(5), 827-831.

- Dunlop, A.-W., & Laws, B. (1997). A response from Autism Scotland. In, *Autism: The Way Forward*. Report of conference held at Strathclyde University.
- Edgerton, C. L. (1994). The effect of improvisational music therapy on the communicative behaviors of autistic children. *Journal of Music Therapy*, 31(1), 31-62.
- Ehlers, S., & Gillberg, C. (1993). The epidemiology of Asperger syndrome: a total population study. *Journal of Child Psychology and Psychiatry*, 34(8), 1327-1350.
- El-Ghorouy, N. H., & Romanczyk, R. G. (1999). Play interactions of family members towards children with autism. *Journal of Autism and Developmental Disorders*, 29(3), 249-258.
- Elder, S. J. M. (2000). *Various chromosomal abnormalities found in autistic individuals: a literature review*. Paper presented at the Autism Europe Congress: Making Our Dream Reality, Glasgow.
- Emerson, A., & Grayson, A. (1996). Changes observed in a man with autism following the introduction of facilitated communication. In G. Linfoot & P. Shattock & R. Finnigan & D. Savery & S. West (Eds.), *Therapeutic Intervention in Autism: Perspectives from Research & Practice*.: University of Sunderland & National Autistic Society.
- Erba, H. W. (2000). Early intervention programs for children with autism: conceptual frameworks for implementation. *American Journal of Orthopsychiatry*, 70(1), 82-94.
- Evans, M. (1989). *Emotional Options: How To Use The Option Method*. California: Yes You Can Press.
- Fein, D., Pennington, B., Markowitz, P., Braverman, M., & Waterhouse, L. (1986). toward a neuropsychological model of infantile autism: are the social deficits primary? *Journal of the American Academy of Child and Adolescent Psychiatry*, 25, 198-212.
- Ferrara, C., & Hill, S. D. (1980). The responsiveness of autistic children to the predictability of social and nonsocial toys. *Journal of Autism and Developmental Disorders*, 10(1), 51-57.
- Folstein, S., & Rutter, M. (1977). Infantile autism: a genetic study of 21 twin pairs. *Journal of Child Psychology and Psychiatry*, 18, 297-321.
- Forsyth, P., Kennedy, H., & Simpson, R. (1996). *Video Interaction Guidance in Schools - We've Looked at Life From Both Sides Now. Scottish Project in Viewing Interaction Positively in Schools*.: Tayside Educational Psychology Service/Association of Scottish Principals of Educational Psychology/SOED.
- Freeman, B. J. (1997). Guidelines for evaluating intervention programs for children with autism. *Journal Of Autism and Developmental Disorders*, 27, 641-651.
- Frith, U. (1989). *Autism: Explaining the Enigma*. Oxford: Blackwell.
- Frith, U. (2000). Cognitive explanations of autism. In K. Lee (Ed.), *Childhood Cognitive Development: The Essential Readings*. Malden, Mass. & Oxford: Blackwell.
- Frith, U., & Happe, F. G. E. (1994). Autism: beyond "theory of mind". *Cognition*, 50, 115-132.
- Gage, J. D., & Wilson, L. J. (2000). Acceptability of attention-deficit/hyperactivity disorder interventions: A comparison of parents. *Journal of Attention Disorders*, 4(3), 174-182.
- Garber, H. J., & Ritvo, E. R. (1992). Magnetic resonance imaging of the posterior fossa in autistic adults. *American Journal of Psychiatry*, 149, 245-247.
- Gath, A. (1979). Parents as therapists of mentally handicapped children. *Journal of Child Psychology and Psychiatry*, 20, 161-165.
- Gerlach, E. K. (1993). *Autism Treatment Guide*. Eugene, Oregon: Four Leaf Press.
- Gillberg, C. (1984). Infantile autism and other childhood psychoses in a Swedish urban region:Epidemiological aspects. *Journal of Child Psychology and Psychiatry*, 25, 35-43.
- Gillberg, C. (1996). Autism and its spectrum disorders. In G. Forrest & P. Vostanis (Eds.), *ACPP Occasional Papers no.13 Advances in the Assessment and Management of Autism*.
- Gillberg, C. (1998). Chromosomal disorders and autism. *Journal of Autism and Developmental Disorders*, 28(5), 415-425.
- Gillberg, C., & Coleman, M. (1996). Autism and medical disorders: a review of the literature. *Dev Med Child Neurol*, 38(3), 191-202.
- Gillberg, C., Steffenburg, S., & Schaumann, H. (1991). Autism: epidemiology: is autism more common now than 10 years ago? *British Journal of Psychiatry*, 158, 403-409.
- Gillberg, I. C., & Gillberg, C. (1989). Asperger Syndrome - some epidemiological considerations: a research note. *Journal of Child Psychology and Psychiatry*, 30, 631-638.
- Ginn, K. (2000, 6th November). Living with Danny. *Scotsman*, pp. 8-9.
- Girolametto, L. (1988). Improving the social-conversation skills of developmentally delayed children: an intervention study. *Journal of Speech and Hearing Disorders*, 53, 156-167.

- Girolametto, L., Tannock, R., & Siegel, L. (1993). Consumer-oriented evaluation of interactive language intervention. *American Journal of Speech-Language Pathology*, 41-51.
- Glaser, B. G., & Strauss, A. L. (1967). *The Discovery of Grounded theory: Strategies for Qualitative Research*. Chicago: Aldine.
- Glossop, C., & Castillo, M. (1982). Summary of present and future research into the Portage model. In R. J. Cameron (Ed.), *Working Together: Portage in the UK*. Windsor: NFER-Nelson.
- Golden, G. S. (1980). Nonstandard therapies in the developmental disabilities. *American Journal of Disabled Children*, 134, 487-491.
- Gould, J. (1993). Facilitated Communication: an overview. *Communication*, 27(2), Reprint produced by National Autistic Society.
- Grantham, E., & Russell, P. (1985). Parents as partners. In M. Griffiths & P. Russell (Eds.), *Working Together with Handicapped Children: Guidelines for Parents and Professionals*. London: Souvenir Press.
- Grayson, A., & Emerson, A. (1996). A systematic microanalysis of facilitated communication involving a client with autism: can fine-grained video analysis contribute to accurate attributions of authorship. In G. Linfoot & P. Shattock & R. Finnigan & D. Savery & S. West (Eds.), *Therapeutic Intervention in Autism: Perspectives from Research & Practice*.: University of Sunderland & National Autistic Society.
- Green, G. (1996). Early Behavioral Intervention for autism: what does research tell us? In C. Maurice & G. Green & S. C. Luce (Eds.), *Behavioral Intervention for Young Children with Autism: A Manual for Parents and Professionals*. Texas: Pro-Ed.
- Greenspan, S., & Wieder, S. (1999). A functional developmental approach to autistic spectrum disorders. *The Journal of the Association for Persons with Severe Handicaps*, 24(3), 147-161.
- Greig, A., & Taylor, J. (1999). *Doing Research with Children*. London: Sage.
- Gresham, F. M. (1996). Treatment integrity in single-subject research. In R. D. Franklin & D. B. Allison (Eds.), *Design and Analysis of Single-Case Research* (pp. 93-117). Hillsdale, NJ, US: Lawrence Erlbaum Associates, Inc.
- Gresham, F. M., Gansle, K. A., & Noell, G. H. (1993). Treatment integrity in applied behavior analysis with children. *Journal of Applied behavior Analysis*, 26(2), 257-263.
- Gresham, F. M., & MacMillan, D. L. (1998). Early Intervention Project: can its claims be substantiated and its effects replicated? *Journal of Autism and Developmental Disorders*, 28(1), 5-13.
- Gresham, F. M., MacMillan, D. L., Beebe-Frankenberger, M. E., & Bocian, K. M. (2000). Treatment integrity in learning disabilities intervention research: do we really know how treatments are implemented? *Learning Disabilities Research and Practice*, 15(4), 198-205.
- Groden, G., & Domingue, D. (1988). Parent and family involvement. In G. Groden & D. Domingue (Eds.), *Autism Strategies for Change: A Comprehensive Approach to the Education and Treatment of Children With Autism and Related Disorders*. New York & London: Gardner Press.
- Guralnick, M. J. (1997). Second-generation research in the field of early intervention. In M. J. Guralnick (Ed.), *The Effectiveness of Early Intervention*. Baltimore: Paul H. Brookes.
- Halle, J. (1998). Fidelity: A crucial question in translating research into practice. *Journal of Early Intervention*, 21(4), 294-296.
- Hamilton, R.S. (2000) Family matters. In Hamilton, L. M. *Facing Autism: Giving Parents Reason For Hope and Guidance For Help*. Colorado: Waterbrook Press.
- Hamilton-Ely, S. P. (1990). The Option Method. *Communication*, 24(1), 7-8.
- Handleman, J. S., Harris, S. L., & Alessandri, M. (1990). Mothers, fathers, teachers and speech therapists as assessors of treatment outcomes for children with autism. *Education and Treatment of Children*, 13(2), 153-158.
- Happe, F. G. E. (1993). Communicative competence and theory of mind in autism: a test of relevance theory. *Cognition*, 48, 101-119.
- Happe, F. G. E. (1994). *Autism: An Introduction to Psychological Theory*. London: UCL Press.
- Happe, F. G. E. (1997). Central coherence and theory of mind in autism: reading homographs in context. *British Journal of Developmental Psychology*, 15, 1-12.
- Happe, F. G. E., Briskman, J., & Frith, U. (2001). Exploring the cognitive phenotype of autism: weak "central coherence" in parents and siblings of children with autism I. Experimental tests. *Journal of Child Psychology and Psychiatry*, 42(3), 299-307.

- Harel, H., Shapiro, Y., & Spierer, Z. (1977). *A follow-up study of children with neurodevelopmental disabilities treated by the Delacato team, abstracted*. Paper presented at the 6th National Meeting of the Child Neurology Society, Charlottesville, Va. Cited in Golden (1980).
- Harris, S. L., & Milch, R. E. (1981). Training parents as behavior therapists for their autistic children. *Clinical Psychology Review*, 1, 49-63.
- Harris, S. L., & Powers, M. D. (1984). Behavior therapists look at the impact of an autistic child on the family system. In E. Schopler (Ed.), *Effects of Autism on the Family*. New York & London: Plenum Press.
- Harris, S. L., Wolchik, S. A., & Weitz, S. (1981). The acquisition of language skills by autistic children: Can parents do the job? *Journal Of Autism and Developmental Disorders*, 11(4), 373-384.
- Hastings, R., & Johnson, E. (2000). *Stress of UK parents running home-based behavioural intervention programmes for their young children with autism*. Paper presented at the British Psychological Society Developmental Section Annual Conference, University of Bristol.
- Hauck, M., Fein, D., Waterhouse, L., & Feinstein, C. (1995). Social initiations by autistic children to adults and other children. *Journal of Autism and Developmental Disorders*, 25(6), 579-595.
- Heath, C. (1997). The analysis of activities in face to face interaction using video. In D. Silverman (Ed.), *Qualitative Research: Theory, Method and Practice*. London: Sage.
- Heberlein, T. A., & Baumgartner, R. (1978). Factors affecting response rates to mailed questionnaires: A quantitative analysis of the published literature. *American Sociological Review*, 43(4), 447-462.
- Hemsley, R., Howlin, P., Berger, M., Hersov, L., Holbrook, D., Rutter, M., & Yule, W. (1978). Treating autistic children in a family context. In M. Rutter & E. Schopler (Eds.), *Autism: A Reappraisal of Concepts and Treatment* (pp. 379-411). New York: Plenum Press.
- Hewett, D. (1989). The most severe learning difficulties: Does your curriculum go back far enough? In M. Ainscow (Ed.), *Special Education in Change*. London: David Fulton.
- Hewett, D., & Nind, M. (1989). Developing an interactive curriculum for pupils with severe and complex learning difficulties: A classroom process. In B. Smith (Ed.), *Interactive Approaches to the Education of Children with Severe Learning Difficulties*. Birmingham: Westhill College.
- Hewett, D., & Nind, M. (1992). Returning to the basics: A curriculum at Harperbury hospital school. In T. Booth & W. Swann & M. Masterton & P. Potts (Eds.), *Learning For All 1: Curricula For Diversity in Education*. London: Routledge.
- Hewett, D., & Nind, M. (1998). *Interaction in Action: Reflections on the Use of Intensive Interaction*. London: David Fulton.
- Hobson, R. P. (1986). The autistic child's appraisal of expressions of emotion. *Journal of Child Psychology and Psychiatry*, 27, 321-342.
- Hobson, R. P. (1991). Against the theory of "theory of mind". *British Journal of Developmental Psychology*, 9, 33-51.
- Hobson, R. P. (1993). *Autism and the Development of Mind*. Hillsdale, NJ: Lawrence Erlbaum Associates.
- Holmes, N., Hemsley, R., Rickett, J., & Likierman, H. (1982). Parents as co-therapists: their perceptions of a home-based behavioral treatment for autistic children. *Journal of Autism and Developmental Disorders*, 12(4), 331-342.
- Hood, S., Kelley, P., & Mayall, B. (1996). Children as research subjects: a risky enterprise. *Children and Society*, 10(2), 117-128.
- Hoshino, Y., Kumashiro, H., Yashima, Y., Tachibana, R., & Watanabe, M. (1982). The epidemiological study of autism in Fukushima-Ken. *Folia Psychiatrica Et Neurologica Japonica*, 36(2), 115-124.
- Houwing, C. (1996). *History and background of video interaction guidance*. Paper presented at the SPIN in Schools Conference.
- Howlin, P. (1984). Parents as therapists: A critical review. In D. J. Muller (Ed.), *Remediating Children's Language: Behavioural and Naturalistic Approaches*. London: Croom Helm.
- Howlin, P. (1996a). Some approaches to modifying problem behaviours in autism. In G. Forrest & P. Vostanis (Eds.), *ACPP Occasional Papers no. 13 Advances in the Assessment and Management of Autism*.
- Howlin, P. (1996b). *A Visit To The Light And Sounds Therapy Centre*. London: The National Autistic Society.
- Howlin, P. (1997). Prognosis in autism: Do specialist treatments affect long-term outcome? *European Child & Adolescent Psychiatry*, 6, 55-72.

- Howlin, P. (1998a). *Children with Autism and Asperger Syndrome: A Guide for Practitioners and Carers*. Chichester: Wiley.
- Howlin, P. (1998b). Practitioner review: Psychological and educational treatments for autism. *Journal of Child Psychology and Psychiatry*, 39, 307-322.
- Howlin, P., & Moore, A. (1997). Diagnosis in autism: A survey of over 1200 patients in the UK. *Autism*, 1(2), 135-162.
- Howlin, P., & Rutter, M. (1987). *Treatment of Autistic Children*. Chichester: Wiley.
- Huff, R. C. (1996). Community-based early intervention for children with autism. In C. Maurice & G. Green & S. C. Luce (Eds.), *Behavioral Intervention for Young Children with Autism: A Manual for Parents and Professionals*. Texas: Pro-Ed.
- Hughes, C., & Russell, J. (1993). Autistic children's difficulty with mental disengagement: its implication for theories of autism. *Developmental Psychology*, 29, 498-510.
- Hughes, C., Russell, J., & Robbins, T. W. (1994). Evidence for executive dysfunction in autism. *Neuropsychologia*, 32(4), 477-492.
- Hutt, S. J., Hutt, C., Lee, D., & Ounsted, C. (1964). Arousal and childhood autism. *Nature*, 204, 908-909.
- Jones, G., Meldrum, E., & Newson, E. (1995). *A Descriptive and Comparative Study of Interventions for Children with Autism*. Nottingham University.
- Jordan, R. (1990). *The Option Approach to Autism: Observer Project Report*. Hatfield Polytechnic.
- Jordan, R. (1991). Two conflicting therapies? The Option method and behaviourism as treatments for the fundamental difficulties in autism. In P. Shattock (Ed.), *Therapeutic Approaches to autism: Research and Practice*. University of Sunderland & National Autistic Society.
- Jordan, R. (1996). Educational programmes for individuals with autism. In G. Forrest & P. Vostanis (Eds.), *ACPP Occasional Papers no.13 Advances in the Assessment and Management of Autism*.
- Jordan, R., & Jones, G. (1996). *Educational Provision for Children with Autism in Scotland*. University of Birmingham: SOEID.
- Jordan, R., Jones, G., & Murray, D. (1998). *Educational interventions for children with autism: a literature review of recent and current research. Research report RR77*. London: DfEE.
- Jordan, R., Libby, S., & Powell, S. (1995). Theories of autism: Why do they matter? *School Psychology International*, 16(3), 291-302.
- Jordan, R., & Powell, S. (1993). Reflections of the Option method as a treatment for autism. *Journal Of Autism and Developmental Disorders*, 23(4), 682-685.
- Jordan, R., & Powell, S. (1996). "Therapist drift": identifying a new phenomenon in evaluating therapeutic approaches. In G. Linfoot & P. Shattock & R. Finnigan & D. Savery & S. West (Eds.), *Therapeutic intervention in autism: Perspectives from Research and Practice*. University of Sunderland & National Autistic Society.
- Jorde, L. B., Hasstedt, S. J., Ritvo, E. R., Mason-Brothers, A., Freeman, B. J., Pingree, C., McMahon, W. M., Peterson, B., Jenson, W. R., & Moll, A. (1991). Complex segregation analysis of autism. *American Journal of Human Genetics*, 49, 932-938.
- Kanner, L. (1943). Autistic disturbances of affective contact. *Nervous Child*, 2, 217-250.
- Kanner, L., & Eisenberg, L. (1956). Early infantile autism 1943-1955. *American Journal of Orthopsychiatry*, 26, 55-65.
- Kaufman, B. N. (1976). *To Love Is To Be Happy With*. Worcester & London: Souvenir Press.
- Kaufman, B. N. (1977). *To Love Is To Be Happy With*. New York: Fawcett Crest.
- Kaufman, B. N. (1979). *Giant Steps*. New York: Fawcett Crest.
- Kaufman, B. N. (1981). *A Miracle To Believe In*. New York: Fawcett Crest.
- Kaufman, B. N. (1991). *Happiness is a Choice*. New York: Fawcett Columbine.
- Kaufman, B. N. (1994). *Son-Rise: The Miracle Continues*. Tiburon, CA.: HJ Kramer Inc.
- Kaufman, S. (1998). The Son-Rise Program at the Option Institute. *Communication, Spring*, 19-23.
- Kazdin, A. E. (1999). Current (lack of) status of theory in child and adolescent psychotherapy research. *Journal of Clinical Child Psychology*, 28, 533-543.
- Kazdin, A. E., & Weisz, J. R. (1998). Identifying and developing empirically supported child and adolescent treatments. *Journal of Consulting and Clinical Psychology*, 66(1), 19-36.
- Keenan, M., Kerr, K. P., & Dillenburger, K. (Eds.). (2000). *Parents' Education as Autism Therapists: Applied Behaviour Analysis in Context*. London & Philadelphia: Jessica Kingsley.
- Kemper, T. L., & Bauman, M. L. (1993). The contribution of neuropathologic studies to the understanding of autism. *Behavioral Neurology*, 11, 175-187.

- Kerr, K. P. (2000). Applied Behaviour Analysis: the treatment of choice. In M. Keenan & K. P. Kerr & K. Dillenburger (Eds.), *Parents' Education as Autism Therapist: Applied Behaviour Analysis in Context*. London: Jessica Kingsley Publishers.
- Kleinman, M. D., Neff, S., & Rosman, N. P. (1992). The brain in infantile autism: are posterior fossa structures abnormal? *Neurology*, 42, 753-760.
- Klin, A., Volkmar, F. R., & Sparrow, S. S. (1992). Autistic social dysfunction: some limitations of the 'theory of mind' hypothesis. *Journal of Child Psychology and Psychiatry*, 33, 861-876.
- Klinger, L. G., & Dawson, G. (1992). Facilitating early social and communicative development in children with autism. In S. F. Warren & J. Reichler (Eds.), *Causes and Effects in Communication and Language Intervention*. Baltimore: Paul Brookes Publishing.
- Knight, C. (1991). Developing communication through interaction. In G. Lloyd & J. Watson (Eds.), *Innovatory Practice and Severe learning Difficulties (Meeting Educational Special Needs: A Scottish Perspective)* (Vol. 1). Edinburgh: Moray House Publications.
- Knight, C., & Watson, J. (1990). *Intensive Interactive Teaching at Gogarburn School*.: Moray House College, Edinburgh.
- Knott, F. (1996). *Approaches to Autism in the USA; Winston Churchill Travelling Fellowship Report*.: Ayrshire Central Hospital.
- Knott, F., Lewis, C., & Williams, T. (1995). Sibling interaction of children with learning disabilities: a comparison of Autism and Down's Syndrome. *Journal of Child Psychology and Psychiatry*, 36(6), 965-976.
- Koegel, R. L., Dyer, K., & Bell, L. K. (1987). The influence of child-preferred activities on autistic children's social behaviour. *Journal of Applied behavior Analysis*, 20, 243-252.
- Koegel, R. L., Rincover, A., & Egel, A. L. (1982). *Educating and Understanding Autistic Children*. San Diego, CA.: College Hill.
- Kolb, B., & Whishaw, I. Q. (1985). *Fundamentals of Human Neuropsychology*. New York: Freeman & Co.
- Kolko, D. J. (1984). Parents as behavioral therapists for their autistic children: clinical and empirical considerations. In E. Schopler (Ed.), *Effects of Autism on the Family*. New York & London: Plenum Press.
- Kozloff, M. A. (1984). A training program for families of children with autism. In E. Schopler (Ed.), *Effects of Autism on the family*. New York & London: Plenum Press.
- Krauss, M. W. (1997). Two generations of family research in early intervention. In M. J. Guralnick (Ed.), *The Effectiveness of Early Intervention*. Seattle: Paul Brookes Publishing Co.
- Kuzel, A. J. (1992). Sampling in qualitative inquiry. In B. F. Crabtree & W. L. Miller (Eds.), *Doing Qualitative Research*. Newbury Pk, CA: Sage.
- Lavigne, H. (1976). The use of siblings as an adjunct to the behavioral treatment of children in the home with parents as therapists. *Behavior Therapy*, 7, 602-613.
- Le Couteur, A., Bailey, A., Goode, S., Pickles, A., Robertson, S., Gottesman, I., & Rutter, M. (1996). A broader phenotype of autism: the clinical picture in twins. *Journal of Child Psychology and Psychiatry*, 37, 785-802.
- LeLaurin, K., & Wolery, M. (1992). Research Standards in Early Intervention - Defining, Describing, and Measuring the Independent Variable. *Journal of Early Intervention*, 16(3), 275-287.
- Leslie, A. M. (1987). Pretense and representation: The origins of 'theory of mind'. *Psychological Review*, 94, 412-426.
- Levy, J. (1999). *Teaching critical social skills: utilizing attitude, environment, joining and motivation in the Son-Rise Program*. Paper presented at the Autism 99 on-line conference, [www.autism99.org](http://www.autism99.org).
- Lewis, A., & Lindsay, G. (Eds.). (2000). *Researching Children's Perspectives*. Buckingham Philadelphia: Open University Press.
- Libby, S., Powell, S., Messer, D., & Jordan, R. (1998). Spontaneous play in children with autism: a reappraisal. *Journal of Autism and Developmental Disorders*, 28(6), 487-497.
- Lloyd, J. M. (1986). *Jacob's Ladder: A Parent's View of Portage*. Kent: Costello.
- Lord, C., Schopler, E., & Revicki, D. (1982). Sex differences in autism. *Journal of Autism and Developmental Disorders*, 12, 317-330.
- Lotter, V. (1966). Epidemiology of autistic conditions in young children I: prevalence. *Social Psychiatry*, 1, 124-137.
- Loumgair, E. (1997). *The Options Treatment Method*. Unpublished Undergraduate dissertation, University of Edinburgh, Edinburgh.

- Lovaas, O. I. (1978). Parents as therapists. In M. Rutter & E. Schopler (Eds.), *Autism: A Reappraisal of Concepts and Treatment* (pp. 369 - 378). New York: Plenum Press.
- Lovaas, O. I. (1987). Behavioural treatment and normal educational and intellectual functioning in young autistic children. *Journal of Consulting and Clinical Psychology*, 55(1), 3-9.
- Lovaas, O. I. (1993). The development of a treatment-research project for developmentally disabled and autistic children. *Journal of Applied behavior Analysis*, 26(4), 617-630.
- Lovaas, O. I. (1996). The UCLA young autism model of service delivery. In C. Maurice & G. Green & S. C. Luce (Eds.), *Behavioral Intervention for Young Children with Autism: A Manual for Parents and Professionals*. Texas: Pro-Ed.
- Lovaas, O. I., Koegel, R. L., Simmons, J. Q., & Long, J. S. (1973). Some generalization and follow-up measures on autistic children in behavior therapy. *Journal of Applied behavior Analysis*, 6, 131-166.
- Luce, S. C., & Dyer, K. (1996). Answers to commonly asked questions. In C. Maurice & G. Green & S. C. Luce (Eds.), *Behavioral Intervention for Young Children with Autism: A Manual for Parents and Professionals*. Texas: Pro-Ed.
- Lynch, S. (1996). Intensive behavioural intervention with a seven year old girl with autism. In G. Linfoot & P. Shattock & R. Finnigan & D. Savery & S. West (Eds.), *Therapeutic Intervention in Autism: Perspectives from Research and Practice*.: University of Sunderland and National Autistic Society.
- Lynch, S. (1998). Intensive behavioural intervention with a 7-year-old girl with autism. *Autism*, 2(2), 181-197.
- MacDonald, H., & MacDonald, A. (1991). Option Method - part two. *Communication*, 25, 5-6.
- Macey, E. (1996). Using the Option approach in schools. In P. Shattock & G. Linfoot (Eds.), *Autism on the Agenda: Papers from a NAS conference 1994*.
- Marcus, L. M. (1984). Coping with burnout. In E. Schopler (Ed.), *Effects of Autism on the Family*. New York & London: Plenum Press.
- Marcus, L. M., Lansing, M., Andrews, C. E., & Schopler, E. (1978). Improvement of teaching effectiveness in parents of autistic children. *Journal of the American Academy of Child and Adolescent Psychiatry*, 17, 625-639.
- Martin, P., & Bateson, P. (1993). *Measuring Behaviour: An Introductory Guide* ( 2nd ed.). Cambridge: Cambridge University Press.
- Mason, J. (1994). Linking qualitative and quantitative data analysis. In A. Bryman & R. G. Burgess (Eds.), *Analyzing Qualitative Data*. London & New York: Routledge.
- Masson, J. (2000). Researching children's perspectives: legal issues. In A. Lewis & G. Lindsay (Eds.), *Researching Children's Perspectives*. Buckingham & Philadelphia: OUP.
- Maurice, C. (1993). *Let Me Hear Your Voice: A Family's Triumph Over Autism*. London: Robert Hale.
- Maurice, C., Green, G., & Luce, S. C. (Eds.). (1996). *Behavioural Intervention for Young Children with Autism: A Manual for Parents and Professionals*. Texas: Pro-Ed.
- May, T. (1993). *Social Research: Issues, Methods & Process*. Buckingham: OUP.
- McCollum, J. A., & Hemmeter, M. L. (1997). Parent-child interaction intervention when children have disabilities. In M. J. Guralnick (Ed.), *The Effectiveness of early Intervention*. Baltimore: Paul H. Brookes.
- McCubbin, H. I., & Patterson, J. M. (1982). Family adaptation to crises. In H. I. McCubbin & A. E. Cauble & J. M. Patterson (Eds.), *Family Stress, Coping and Social Support* (pp. 26-47). Springfield, IL.: Charles C. Thomas.
- McCubbin, H. I., & Patterson, J. M. (1983). The family stress process: the double ABCX model of adjustment and adaptation. In H. I. McCubbin & M. B. Sussman & J. M. Patterson (Eds.), *Social Stress and the Family: Advances and Developments in Family Stress Theory and Research* (pp. 7-37). New York: Haworth Press.
- McEachin, J. J., Smith, T., & Lovaas, O. I. (1993). Long-term outcome for children with autism who received early intensive behavioural treatment. *Am J Ment Retard*, 97(4), 359-372.
- McHale, S. M., Simonsson, R. J., & Sloan, J. L. (1984). Children with handicapped brothers and sisters. In E. Schopler (Ed.), *Effects of Autism on the Family*. New York & London: Plenum Press.
- Miles, M. B., & Huberman, A. M. (1994). *Qualitative Data Analysis* ( 2nd ed.). Beverly Hills, CA: Sage.
- Miller, N. B., & Cantwell, D. P. (1976). Siblings as therapists: a behavioral approach. *American Journal of Psychiatry*, 133(4), 447-450.
- Minuchin, S. (1974). *Families and Family Therapy*. London: Tavistock Publications.



- Mirenda, P., & Donnellan, A. M. (1986). Effects of adult interaction style on conversational behavior in students with severe communication problems. *Language, Speech & Hearing Services in the Schools*, 17, 126-141.
- Mittler, P., & McConachie, H. (1983). *Parents, Professionals and Mentally Handicapped People: Approaches to Partnership*. London: Croom Helm.
- Moncher, F. J., & Prinz, R. J. (1991). Treatment fidelity in outcome studies. *Clinical Psychology Review*, 11(3), 247-266.
- Moore, B., & Bailey, J. S. (1973). Social punishment in the modification of a preschool child's autistic like behavior. *Journal of Applied Behavior Analysis*, 6(3), 497-507.
- Moreland, J. R., Schwebel, A. I., Beck, S., & Wells, R. (1982). Parents as therapists: a review of the behavior therapy parent training literature 1975 - 1981. *Behavior Modification*, 6(2), 250-276.
- Mudford, O. C., Martin, N. T., Eikeseth, S., & Bibby, P. (2001). Parent-managed behavioral treatment for preschool children with autism: some characteristics of UK programs. *Research in Developmental Disabilities*, 22, 173-182.
- Muller, P., & Warwick, A. (1993). The effects of maternal involvement in therapy. In M. Heal & A. Wigram (Eds.), *Music Therapy in Health and Education*. London & Philadelphia: Jessica Kingsley Publishers.
- Muncie, J., Wetherell, M., Dallos, R., & Cochrane, A. (1995). *Understanding the Family*. London: Sage.
- Mundy, P., & Sigman, M. (1989). Specifying the nature of the social impairment in autism. In G. Dawson (Ed.), *Autism: Nature, Diagnosis & Treatment*. New York & London: Guilford Press.
- Munn, P., & Drever, E. (1990). *Using Questionnaires in Small-Scale Research: A Teacher's Guide*. Edinburgh: The Scottish Council for Research in Education.
- Nelson, K. B., Grether, J. K., Croen, L. A., Dambrosia, J. M., Dickens, B. F., Jelliffe, L. L., Hansen, R. L., & Phillips, T. M. (2001). Neuropeptides and neurotrophins in neonatal blood of children with autism or mental retardation. *Annals of Neurology*, 49, 597-606.
- Nickel, R. E. (1996). Controversial therapies for young children with developmental disabilities. *Infants and Young Children*, 8(4), 29-40.
- Nickel, R. E., & Stratton, J. (1995). Unpublished data, cited in Nickel, R.E. (1996).
- Niemann, G. W. (1996). The neurodevelopment of autism: recent advances. In G. Forrest & P. Vostanis (Eds.), *ACPP Occasional Papers no. 13 Advances in the Assessment and Management of Autism*.
- Nind, M. (1993). *Access to Communication: Efficacy of Intensive Interaction Teaching for People with Severe Developmental Disabilities*. Unpublished PhD thesis, Cambridge Institute of Education.
- Nind, M. (1996). Efficacy of intensive interaction: developing sociability and communication in people with severe and complex learning difficulties using an approach based on caregiver-infant interaction. *European Journal of Special Needs Education*, 11(1), 48-66.
- Nind, M. (1997a). *Communication with learners who don't know how: Using intensive interaction with learners with autism*. Paper presented at the British Educational Research Association Annual Conference, University of York.
- Nind, M. (1997b). *Is intensive interaction a useful and appropriate approach when learning disabilities are compounded by autism?* Paper presented at the British Institute of Learning Disabilities International Conference: Services Challenged by Complex Needs, Manchester.
- Nind, M., & Hewett, D. (1994). *Access to Communication: Developing the Basics of Communication with People with Severe Learning Difficulties*. London: David Fulton.
- Noldus, L. P. J. J., Trienes, R. J. H., Hendriksen, A. H. M., Jansen, H., & Jansen, R. G. (2000). The Observer Video-Pro: new software for the collection, management and presentation of time-structured data from videotapes and digital media files. *Behavior Research Methods, Instruments & Computers*, 32(1), 197-206.
- Nordoff-Robbins Music Therapy UK. (2000). *Nordoff-Robbins Music Therapy*, [website]. Available: <http://www.nordoff-robbins.org.uk> [2000].
- Norris, J. A., & Hoffman, P. R. (1990). Comparison of adult-initiated vs. child-initiated interaction styles with handicapped prelanguage children. *Language, Speech & Hearing Services in the Schools*, 21, 28-36.
- O' Dell, S. (1974). Training parents in behaviour modification: a review., 81(7), 418-433.
- Ozonoff, S., & Cathcart, K. (1998). Effectiveness of a home program intervention for young children with autism. *Journal of Autism and Developmental Disorders*, 28(1), 25-32.



- Ozonoff, S., & Miller, J. N. (1995). Teaching ToM: a new approach to social skills training for individuals with autism. *Journal of Autism and Developmental Disorders*, 25(4), 415-433.
- Ozonoff, S., Pennington, B., & Rogers, S. (1991). Executive function deficits in high functioning autistic children. *Journal of Child Psychology and Psychiatry*, 32, 1081-1105.
- Parents for the Early Intervention of Autism in Children (PEACH). (1998). *Information Pack (unpublished)*. London.
- Peck, (1985). Increasing opportunities for social control by children with autism and severe handicaps: effects on student behavior and perceived classroom climate. *Journal of the Association for Persons with Severe Handicaps*, 10(4), 183-193.
- Peeters, T. (1997). *From Theoretical Understanding To Educational Intervention*. London: Whurr Publishers Ltd.
- Pennington, B. F., & Ozonoff, S. (1996). Executive functions and developmental psychopathology. *Journal of Child Psychology and Psychiatry*, 37(1), 51-87.
- Perner, J., Frith, U., Leslie, A. M., & Leekam, S. R. (1989). Exploration of the autistic child's theory of mind: knowledge, belief and communication. *Child Development*, 60, 689-700.
- Peterson, C. C., & Siegel, M. (1995). Deafness, conversation, and theory of mind. *Journal of Child Psychology and Psychiatry*, 36, 459-474.
- Piven, J., Gayle, J., Chase, J., Fink, B., Landa, R., Wzorek, M., & Folstein, S. (1990). A family history study of neuropsychiatric disorders in the adult siblings of autistic individuals. *Journal of the American Academy of Child and Adolescent Psychiatry*, 29, 177-183.
- Platt, J. (1988). What can case studies do? In R. G. Burgess (Ed.), *Studies in Qualitative Methodology*. London: JAI Press.
- Prior, M., & Cummins, R. (1992). Questions about facilitated communication and autism. *Journal of Autism and Developmental Disorders*, 22, 331-337.
- Prizant, B., & Duchan, J. (1981). The functions of immediate echolalia in autistic children. *Journal of Speech and Hearing Disorders*, 46, 241-249.
- Prizant, B., & Rubin, E. (1999). Contemporary issues in interventions for autism spectrum disorders: a commentary. *The Journal of the Association for Persons with Severe Handicaps*, 24(3), 199-208.
- Pugh, G. (1981). *Parents as Partners: Intervention Schemes and Group Work With Parents of Handicapped Children*. London: National Children's Bureau.
- Rapin, I., & Katzman, R. (1998). Neurobiology of autism. *Annals of Neurology*, 43(1), 7-14.
- Rappaport, M. D. (2001). Bridging theory and practice: conceptual understanding of treatments for children with attention deficit hyperactivity disorder (ADHD), obsessive-compulsive disorder, autism, and depression. *Journal of Clinical Child Psychology*, 30(1), 3-7.
- Richer, J., & Zappella, M. (1989). Changing social behaviour: the place of holding. *Communication*, 23(2), 35-39.
- Rimland, B., & Edelson, S. M. (1995). Brief report: a pilot study of auditory integration training in autism. *Journal of Autism and Developmental Disorders*, 25(1), 61-70.
- Ritvo, E. R., Freeman, B. J., Scheibel, A. B., Duong, T., Robinson, H., Guthrie, D., & Ritvo, A. (1986). Lower purkinje cell counts in the cerebella of four autistic subjects: initial findings of the UCLA-NSAC Autopsy Research Report. *American Journal of Psychiatry*, 143, 862-866.
- Ritvo, E. R., Spence, M. A., Freeman, B. J., Mason-Brothers, A., Mo, A., & Marazita, M. L. (1985). Evidence for autosomal recessive inheritance in 46 families with multiple incidences of autism. *American Journal of Psychiatry*, 142, 187-192.
- Robbins, F. R., Dunlap, G., & Plien, A. J. (1991). Family characteristics, family training, and the progress of young children with autism. *Journal of Early Intervention*, 15(2), 173-184.
- Roberts, Y. (1996, 13th April). John's Story. *The Daily Express*.
- Rogers, S. (1999). Intervention for young children with autism: from research to practice. *Infants and Young Children*, 12(2), 1-16.
- Rogers, S. (1998). Empirically supported comprehensive treatments for young children with autism. *Journal of Clinical Child Psychology*, 27(2), 167-178.
- Rogers, S. J., Herbison, J. M., Lewis, H. C., Pantone, J., & Reis, K. (1986). An approach for enhancing the symbolic, communicative, and interpersonal functioning of young children with autism or severe emotional handicaps. *Journal for the Division for Early Childhood*, 10(2), 135-148.
- Runco, M. A., & Schreibman, L. (1983). Parental judgements of behavior therapy efficacy with autistic children: A social validation. *Journal of Autism and Developmental Disorders*, 13(3), 237-248.

- Rutter, M. (1996). Autism research: prospects and priorities. *Journal of Autism and Developmental Disorders*, 26(6), 257-275.
- Rutter, M., Bailey, A., Bolton, P., & Le Couteur, A. (1993). Autism: syndrome definition and possible genetic mechanisms. In R. Plomin & G. E. McClearn (Eds.), *Nature, nurture, and psychology*. Washington, DC: APA Books. Cited in Bailey et al (1996).
- Salend, S. J. (1983). Minimizing integrity-of treatment violations. *Exceptional Children*, 50(2), 179-181.
- Samuel, J., & Maggs, J. (1998). Introducing Intensive Interaction for people with profound learning disabilities living in small staffed houses in the community. In D. Hewett & M. Nind (Eds.), *Interaction in Action: Reflections on the Use of Intensive Interaction*. London: David Fulton Publishers.
- Sanders, J. L., & Morgan, S. B. (1997). Family stress and adjustment as perceived by parents of children with autism or Down syndrome: implications for intervention. *Child and family Behavior Therapy*, 19(4), 15-32.
- Sattler, J. M. (1982). *Assessment of Children's Intelligence and Special Abilities*. Boston: Allyn and Bacon inc.
- Schaefer, G. B., Thompson, J. N., Bodensteiner, J. B., McConnell, J. M., Kimberling, W. J., Gay, C. T., Dutton, W. D., Hutchings, D. C., & Gray, S. B. (1996). Hypoplasia of the cerebellar vermis in neurogenetic syndromes. *Annals of Neurology*, 39(3), 382-385.
- Schopler, E. (1978). Changing parental involvement in behavioural treatment. In M. Rutter & E. Schopler (Eds.), *Autism: A Reappraisal of Concepts and Treatment*. New York: Plenum Press.
- Schopler, E., Short, A., & Mesibov, G. B. (1989). Relation of behavioural treatment to 'normal functioning': Comment on Lovaas. *Journal of Consulting and Clinical Psychology*, 57, 162-164.
- Schopler, E., & Mesibov, G. B. (1984). Professional attitudes toward parents: a forty-year progress report. In E. Schopler (Ed.), *Effects of Autism on the Family*. New York & London: Plenum Press.
- Schopler, E., Mesibov, G. B., & Baker, A. (1982). Evaluation of treatment for autistic children and their parents. *Journal of the American Academy of Child Psychiatry*, 21(3), 262-267.
- Schopler, E., Mesibov, G. B., Shigley, R. H., & Bashford, A. (1984). Helping autistic children through their parents: The TEACCH model. In E. Schopler (Ed.), *Effects of Autism on the Family*. New York & London: Plenum Press.
- Schopler, E., & Reichler, R. J. (1971a). Parents as co-therapists in the treatment of psychotic children. *Journal of Autism and Childhood Schizophrenia*, 1(1), 87-102.
- Schopler, E., & Reichler, R. J. (1971b). Developmental therapy by parents with their own autistic child. In M. Rutter (Ed.), *Infantile Autism: Concepts, Characteristics, Treatment*. London: Churchill-Livingstone.
- Schopler, E., & Reichler, R. J. (1972). How well do parents understand their own psychotic children? *Journal of Autism and Childhood Schizophrenia*, 2, 387-400.
- Schopler, E., Van Bourgondien, M. E., & Bristol, M. M. (Eds.). (1993). *Preschool Issues in Autism*. New York & London: Plenum Press.
- Schreibman, L., Koegel, R. L., Mills, D. L., & Burke, J. C. (1984). Training parent-child interactions. In E. Schopler (Ed.), *Effects of Autism on the Family*. New York & London: Plenum Press.
- Scott, J. (1996). Recruiting, selecting, and training teaching assistants. In C. Maurice & G. Green & S. C. Luce (Eds.), *Behavioral Intervention for Young Children with Autism: A Manual for Parents and Professionals*. Texas: Pro-Ed.
- Selikowitz. (1997). *Down Syndrome: The Facts* ( 2nd ed.). Oxford & New York: OUP.
- Shah, A., & Frith, U. (1983). An islet of ability in autistic children: a research note. *Journal of Child Psychology and Psychiatry*, 24, 613-620.
- Shah, A., & Frith, U. (1993). Why do autistic individuals show superior performance on the block design task? *Journal of Child Psychology and Psychiatry*, 34(8), 1351-1364.
- Shattock, P. (1999). *Environmental factors in the causation of autism*. Paper presented at the Autism 99 On-Line Conference, <http://www.autism99.org>.
- Sheinkopf, S. J., & Siegel, B. (1998). Home-based behavioural treatment of young children with autism. *Journal of Autism and Developmental Disorders*, 28(1), 15-23.
- Sheppard, S. (1996). The implementation of Sherborne based developmental movement with pupils on the autistic continuum. In G. Linfoot & P. Shattock & R. Finnigan & D. Savery & S. West (Eds.), *Therapeutic Intervention in Autism: Perspectives from Research & Practice*.: University of Sunderland & National Autistic Society.

- Shields, J. (1999). *The NAS Earlybird programme: autism-specific early intervention for parents of a pre-school child with autistic spectrum disorder*. Paper presented at the Autism 99 On-Line Conference, <http://www.autism99.org>.
- Short, A. B. (1984). Short-term treatment outcome using parents as co-therapists for their own autistic children. *Journal of Child Psychology and Psychiatry*, 25(3), 443-458.
- Siegel, B. (1996). *The World of the Autistic Child: Understanding and Treating Autistic Spectrum Disorders*.: Oxford University Press.
- Sigman, M., & Capps, L. (1997). *Children with Autism: a Developmental Perspective*. Cambridge, MA.: Harvard University Press.
- Sigman, M., & Kasari, C. (1995). Joint attention across contexts in normal and atypical children. In C. Moore & P. Dunham (Eds.), *Joint Attention: Its Origin and Role in Development*. Hillsdale, NJ: Erlbaum.
- Silverman, D. (2000). *Doing Qualitative Research: A Practical Handbook* ( 1st ed.). London: Sage.
- Simpson, R. (1999). Early intervention with children with autism: the search for best practices. *The Journal of the Association for Persons with Severe Handicaps*, 24(3), 218-221.
- Simpson, R., Forsyth, P., & Kennedy, H. (1994). An evaluation of video interaction analysis in families and teaching situations, *Professional Development Initiatives 1993-1994*.: SOED/Regional Psychological Services.
- Smith, B., Chung, M. C., & Vostanis, P. (1994). The path to care in autism: is it better now? *Journal of Autism and Developmental Disorders*, 24, 551-563.
- Sodian, B., & Frith, U. (1992). Deception and sabotage in autistic, retarded and normal children. *Journal of Child Psychology and Psychiatry*, 33(3), 591-605.
- Steffenburg, S., & Gillberg, C. (1986). Autism and autistic-like conditions in Swedish rural and urban areas: a population study. *British Journal of Psychiatry*, 149, 81-87.
- Steffenburg, S., Gillberg, C., Helgren, L., Anderson, L., Gillberg, L., Jakobsson, G., & Bohman, M. (1989). A twin study of autism in Denmark, Finland, Iceland, Norway and Sweden. *Journal of Child Psychology and Psychiatry*, 30, 405-416.
- Stehli, A. (Ed.). (1995). *Dancing In The Rain: Stories of Exceptional Progress By Parents of Children With Special Needs*. Westport, CT.: The Georgiana Organization, Inc.
- Sterling-Turner, H. E., Watson, T. S., Wildmon, M., Watkins, C., & Little, E. (2001). Investigating the relationship between training type and treatment integrity. *school Psychology Quarterly*, 16(1), 56-67.
- Stothard, V. (1998). The gradual development of Intensive Interaction in a school setting. In D. Hewett & M. Nind (Eds.), *Interaction in Action: Reflections on the Use of Intensive Interaction*. London: David Fulton Publishers.
- Strain, P. S. (1987). Comprehensive evaluation of intervention for young autistic children. *Topics in Early Childhood Special Education*, 7(2), 97-110.
- Sussman, F. (1999). *More Than words: The Hanen Program for Parents of Children with Autistic Spectrum Disorder*. Toronto: Hanen Centre Publications.
- Swettenham, J. (1995). Can children with autism be taught to understand false beliefs using computers? *Journal of Child Psychology and Psychiatry*, 37, 157-166.
- Swettenham, J. (1996). The early diagnosis of autism: screening at 18 months of age. In G. Forrest & P. Vostanis (Eds.), *ACPP Occasional Papers No.13: Advances in the Assessment and Management of Autism*.
- Tannock, R., Girolametto, L., & Siegel, L. (1992). The interactive model of language intervention: evaluation of its effectiveness for pre-school-aged children with developmental delay. *American Journal of Mental Retardation*, 97(2), 145-160.
- Taplin, P. S., & Reid, J. B. (1973). Effects of instructional set and experimenter influenced on observer reliability. *Child Development*, 44(3), 547-554.
- Taylor, B., & Taylor, S. (1998). Gary's story: parents doing Intensive Interaction. In D. Hewett & M. Nind (Eds.), *Interaction in Action: Reflections on the Use of Intensive Interaction*. London: David Fulton Publishers.
- Telzrow, C. F. (1993). Commentary on comparative evaluation of early intervention alternatives. *Early Education and Development*, 4(4), 359-365.
- The Committee on Safety of Medicines & the Medicines Control Agency. (2001). MMR vaccine: the facts. *Current Problems in Pharmacovigilance*, 27, 1-3.

- The Option Institute and Fellowship. (1996/97). *The Son-Rise Program Manual: For Families with Special Children*. Sheffield, MA.: The Option Institute and Fellowship.
- The Option Institute and Fellowship. (1998). The Option Institute, [website]. Available: <http://www.happiness.org> [1998].
- Tiegerman, E., & Primavera, L. (1981). Object manipulation: an interactional strategy with autistic children. *Journal of Autism and Developmental Disorders*, 11(4), 427-438.
- Tissot, C. (1999). *Decisions after diagnosis: a practical path for parents*. Paper presented at the autism99 on-line conference, <http://www.autism99.org>.
- Tomasello, M., & Farrar, M. J. (1986). Joint attention and early language. *Child Development*, 57, 1454-1463.
- Trevarthen, C., Aitken, K., Papoudi, D., & Robarts, J. (1998). *Children With Autism: Diagnosis and Interventions to Meet Their Needs* (2nd ed.). London: Jessica Kingsley Publishers.
- Tsai, L. Y. (1999). Recent neurological research in autism. In D. B. Zager (Ed.), *Autism: Identification, Education and Treatment*. New Jersey & London: Lawrence Erlbaum Associates.
- Volkmar, F. R., & Cohen, D. J. (1989). Disintegrative disorder or 'late onset' autism? *Journal of Child Psychology and Psychiatry*, 30, 717-724.
- Wakefield, A., Murch, S. H., Anthony, A., Linnell, J., Casson, D. M., Malik, M., Berelowitz, M., Dhillon, A. P., Thomson, M. A., Harvey, P., Valentine, A., Davies, S. E., & Walker-Smith, J. A. (1998). Ileal-lymphoid-nodular hyperplasia, non-specific colitis, and pervasive developmental disorder in children. *Lancet*, 351, 637-641.
- Walters, T. (1994). Kieran's new world. *Nursery World*, Nov, 10-11.
- Warwick, A. (1997). Music therapy. In *Approaches to Autism*. London: National Autistic Society.
- Waters, L. (1990). Reinforcing the empty fortress: an examination of recent research into the treatment of autism. *Educational Studies*, 16(1), 3-16.
- Watling, R., Deitz, J., Kanny, E. M., & McLaughlin, J. F. (1999). Current practice of occupational therapy for children with autism. *The American Journal of Occupational Therapy*, 53(5), 498-505.
- Watson, J., & Fisher, A. (1997). Evaluating the effectiveness of intensive interactive teaching with pupils with profound and complex learning difficulties. *British Journal of Special Education*, 24(2), 80-87.
- Watson, S., & Boucher, J. (1996). The effectiveness of non-directive therapy in the treatment of pre-school autistic children: an overview of work in progress. In G. Linfoot & P. Shattock & R. Finnigan & D. Savary & S. West (Eds.), *Therapeutic intervention in autism: Perspectives from Research and Practice*. University of Sunderland & National Autistic Society.
- Weeks, S. J., & Hobson, R. P. (1987). The salience of facial expression for autistic children. *Journal of Child Psychology and Psychiatry*, 28, 137-152.
- Wehman, T. (1998). Family-centered early intervention services: factors contributing to increased parent involvement and participation. *Focus on Autism and Other Developmental Disabilities*, 13(2), 80-86.
- Welch, M. (1983). Retrieval from autism through mother-child holding therapy. In N. Tinbergen & E. A. Tinbergen (Eds.), *Autistic Children: New Hope For a Cure*. London: Allen & Unwin.
- White, M., & Cameron, R. J. (1987). *Portage Early Education Programme: A Practical Manual*. Windsor, Berkshire: NFER-Nelson.
- Wimporoy, D., Chadwick, P., & Nash, S. (1995). Brief report: musical interaction therapy for children with autism: an evaluative case study with two-year follow-up. *Journal of Autism and Developmental Disorders*, 25(5), 541-552.
- Wing, L. (Ed.). (1966). *Early Childhood Autism: Clinical, Educational & Social Aspects*. Oxford: Pergamon Press.
- Wing, L. (1980). Childhood autism and social class: A question of selection. *British Journal of Psychiatry*, 137, 410-417.
- Wing, L. (1981). Sex ratios in early childhood autism and related conditions. *Psychiatry Research*, 5, 129-137.
- Wing, L. (1993). The definition and prevalence of autism: A review. *European Child & Adolescent Psychiatry*, 2(2), 61-74.
- Wing, L. (1996a). *The Autistic Spectrum: A Guide for Parents and Professionals*. London: Constable.
- Wing, L. (1996b). Autistic spectrum disorders: no evidence for or against an increase in prevalence. *British Medical Journal*, 312, 327-328.
- Wing, L. (1997a). The autistic spectrum. *Lancet*, 350, 1761-1766.
- Wing, L. (1997b). The history of ideas on autism: legends, myths and reality. *Autism*, 1(1), 13-25.

- Wing, L., & Attwood, T. (1987). Syndromes of autism and atypical development. In D. J. Cohen & A. M. Donnellan & R. Paul (Eds.), *Handbook of Autism and Pervasive Developmental Disorders*. New York: John Wiley.
- Wing, L., & Gould, J. (1979). Severe impairments of social interaction and associated abnormalities in children: epidemiology and classification. *Journal of Autism and Developmental Disorders*, 9(11-29).
- Zelazo, P. D., Burack, J. A., Benedetto, E., & Frye, D. (1996). Theory of mind and rule use in individuals with Down's syndrome: a test of the uniqueness and specificity claims. *Journal of Child Psychology and Psychiatry*, 37, 497-484.
- Zentall, S. S., & Zentall, T. R. (1983). Optimal stimulation: a model of disordered activity and performance in normal and deviant children. *Psychological Bulletin*, 94, 446-471.
- Zigler, E. (1981). A plea to end the use of patterning treatment for retarded children. *American Journal of Orthopsychiatry*, 51, 388-390.
- Zigler, E. (1984). Handicapped children and their families. In E. Schopler (Ed.), *Effects of Autism on the Family*. New York & London: Plenum Press.

# APPENDIX A

## ETHICAL ISSUES

### A1 Introduction

Whilst ethical considerations are important in any piece of research, the nature of the studies in this thesis raised a particular set of issues. A number of the studies involved audio and video recordings which took place in the home. The research was also longitudinal and explored issues of family functioning. Potentially these factors meant that the research could be very intrusive for the families involved, and care had to be taken to ensure that their privacy was respected. Undertaking research with children, particularly those with disabilities, also invokes specific ethical concerns (Greig & Taylor, 1999). Addressing ethical issues appropriately was therefore of central importance, not only at the design stage but throughout the research process.

### A2 Ethical procedures

The British Psychological Society Code of Conduct (2000) was adhered to at all stages of the research. Before each study commenced the nature of the research was explained to the parents, and their potential role in it explained. It was made clear that parents could withdraw from the research at any stage. Parents were also assured that all personal information provided would be treated as confidential, and that neither their child nor their family would be identified by name in the published research material, with pseudonyms being used throughout the thesis. Studies 3 - 5 involved audio and video recordings, and parents were informed that only those directly concerned with the research would have access to these.

Particular attention was paid to the issue of advice. It was made clear that although the researcher was trained and experienced in use of the Son-Rise techniques, advice could not be given to the families on their own Son-Rise Program. Such information could be a source of potential bias in the research, and equally importantly may have been less appropriate than the advice provided by the Option Institute. In the event that parents did seek feedback from the researcher they were advised that contacting the Option Institute would be the best course of action.

Following discussion of these issues parents were given the opportunity to ask any questions they had about the research. If they were then agreeable to becoming involved they were asked to sign a form consenting to audio/video recordings taking place. After this initial agreement ongoing consent in the longitudinal studies was not assumed, but confirmed either verbally or in writing on each occasion.

The interview research, Studies 3 and 5, explored family functioning and the ways in which families adapted the SRP to suit their own child and family circumstances. These were potentially sensitive topics and efforts were made to explore them in a respectful manner. Pilot interviews were undertaken to confirm that the questions were worded sensitively, and before the interviews it was emphasised to the parents that questions were not intended to be judgmental in any way.

In the questionnaire research, studies 1 and 2, similar pilot work was undertaken with parents of children with autism. In the case of study 2 modifications to the first questionnaire were also

made as result of feedback from the Option Institute. This resulted in a questionnaire which was more sensitively worded, to avoid undermining parents' confidence in their ability to run an SRP.

At the end of the interview and video studies the experience of the research process was discussed with the participants to ensure that there had been no unintended or unanticipated adverse effects of participating in the research (Barrett, 1995). At the end of each interview the mothers were asked if there was anything which, on reflection, they would have preferred not to have had taped and informed that this could be removed from the transcript. In practice, there was nothing which the mothers wished removed from transcripts. As with audio recordings, there is also literature to suggest that the presence of an observer making video recordings may have an effect on study participants (Cohen *et al*, 2000; Martin & Bateson, 1993). At the end of the video study therefore, parents were asked whether the presence of the researcher in the playroom had had any effect on them, either beneficially or detrimentally. Two of the mothers felt that the presence of an observer had been beneficial, as it had made each implement the techniques more effectively. Two mothers said it had made them slightly self-conscious, particularly initially, but none felt that it had caused them any serious difficulties or concern.

### **A3 Ethical considerations when research takes place in the home**

The privacy of the home has high value. For researchers who are also strangers to enter the home and ask questions, however sympathetic, is an invasion (Hood, Kelley, & Mayall, 1996). Both the interview and video studies took place in the families' homes, and care was taken throughout to respect the privacy of each family. For example, in the video study it was periodically confirmed that the parents did not find the time commitment unacceptable or the researcher's presence too intrusive. Although filming sessions were intended to take place at precise and regular intervals, they were re-scheduled if this was inconvenient for the family at any time.

### **A4 Ethical considerations when working with children with autism**

Given the age and verbal ability of the children involved in the video study it was not possible to obtain their verbal consent to participate. Consent by proxy was therefore obtained from the parents. Parents were provided with information about the child's role in the research in order to allow them to make an informed decision about permitting their involvement (Masson, 2000). Mindful of the limited verbal ability of the children involved in the video study, particular attention was paid to any signs of distress by the child, or indications that they did not wish to be filmed, bearing in mind that children with autism sometimes have idiosyncratic ways of conveying emotions (Cohen, 1998; Wing, 1996). In cases where the child appeared to be upset, clarification was sought from the mother over whether she felt it prudent to terminate the filming session.

It was important that during filming sessions the presence of the researcher did not prevent the parents from providing the most effective therapy possible for their child. Attempts were thus made to minimise any disruption that filming caused the child. For example interaction between the researcher and the child was, as far as possible, kept to a minimum immediately prior to the filming so that the child would not be distracted by the presence of the researcher in the playroom. This was particularly important given the difficulty some children with autism have in paying attention to relevant stimuli (Peeters, 1997).

## A5 Overview

As much of this research focused on the family and took place in the home, with some families participating for over a year, it was potentially intrusive for all of those involved. Ethical procedures were adopted which aimed to keep such effects to a minimum. British Psychological Society guidance on the involvement of children was followed, with particular consideration of the effect that the children's autism might have on their experience of participation in the research.

## References

- Barrett, M. (1995). Practical and ethical issues in planning research. In G. M. Breakwell & S. Hammond & C. Fife-Schaw (Eds.), *Research Methods in Psychology*. London: Sage.
- British Psychological Society. (2000). *Code of Conduct, Ethical Principles and Guidelines*. Leicester: BPS. Available at <http://www.bps.org.uk>
- Cohen, D. J., Manion, L., & Morrison, K. (2000). *Research Methods in Education*. London & New York: Routledge.
- Cohen, S. (1998). *Targeting Autism: What We Know, Don't Know, And Can Do to Help Young Children with Autism and Related Disorders*. Berkeley: University of California Press.
- Greig, A., & Taylor, J. (1999). *Doing Research with Children*. London: Sage.
- Hood, S., Kelley, P., & Mayall, B. (1996). Children as research subjects: a risky enterprise. *Children and Society*, 10(2), 117-128.
- Martin, P., & Bateson, P. (1993). *Measuring Behaviour: An Introductory Guide* ( 2nd ed.). Cambridge: Cambridge University Press.
- Masson, J. (2000). Researching children's perspectives: legal issues. In A. Lewis & G. Lindsay (Eds.), *Researching Children's Perspectives*. Buckingham & Philadelphia: OUP.
- Peeters, T. (1997). *From Theoretical Understanding To Educational Intervention*. London: Whurr Publishers Ltd.
- Wing, L. (1996). *The Autistic Spectrum: A Guide for Parents and Professionals*. London: Constable.



**APPENDIX B**

**INTERVENTION USE QUESTIONNAIRE (STUDY 1)**

### APPROACHES TO AUTISM QUESTIONNAIRE

I am a PhD student at Moray House Institute of Education in Edinburgh, carrying out research into different kinds of approaches being used with children with autism. This questionnaire is designed to gain a clearer picture of interventions that are being used in the Lothian region, in an attempt to identify those methods best suited to help children with autism. If you can spare the time to fill out this short questionnaire and return it in the envelope provided, *by 28th Feb 1998*, I would be very grateful. Lothian Autistic Society has kindly agreed to collaborate in this research and to help in distributing the questionnaires. Any personal information provided in the returned questionnaires will be considered strictly confidential. If you have any queries before returning it, however, please feel free to contact me directly on 558 6539.

Many Thanks,  
Katie Williams

### SECTION 1 - FAMILY INFORMATION

(1) Name of parent/guardian completing this questionnaire

Surname ..... Forename .....

(2) Address .....

.....

..... Postcode .....

(3) How many of your children have been identified as having an autistic spectrum disorder (e.g. autism, Asperger syndrome, autistic tendencies) ? .....

If you have two or more children who have an autistic spectrum disorder please complete this questionnaire for the eldest of the children, and a further questionnaire will be sent to you to complete for the other child(ren).

(4) Date of birth of child ...../...../.....

(5) Specific diagnosis given (*please tick correct box*).

DIAGNOSIS	✓	DIAGNOSIS	✓
Autism		Autistic tendencies	
Asperger Syndrome		Awaiting diagnosis	
Other ( <i>please specify</i> )			

(5a) Approximate age when diagnosed .....

(6) Has your child any learning difficulties or physical problems in addition to autism?

Yes/No (*delete as appropriate*).

If yes, please describe:

.....  
.....  
.....

(7) Who does your child spend the 'school day' with (i.e. 9am - 3pm) ?

*Please tick the appropriate boxes.*

SUPERVISION	AM(✓)	PM (✓)
Childcare from parent(s)		
Childcare from other (e.g. relative/childminder)		
At preschool (e.g. playgroup/nursery) ( <i>Please give name</i> )		
.....		
At school ( <i>Please give name</i> )		
.....		
Other ( <i>Please specify</i> )		
.....		

## SECTION 2 - CURRENT AND PREVIOUS INVOLVEMENT IN APPROACHES OUTWITH SCHOOL

(8) Has your child been involved in any of the following approaches, including any you follow(ed) in your own home? If none, please continue overleaf.

Exclude any which were carried out only in nursery/ playschool/ school.

Please tick any appropriate boxes and give relevant dates

APPROACH	✓	DATE BEGUN (mth/yr)	END DATE (if intervention has ended)	EXPECTED END DATE (if intervention has not yet ended)
Auditory Integration Training (Berard's Method)				
Augmented communication (eg signs, pictures or symbols such as Makaton)				
Behaviour Modification (e.g. Lovaas)				
Conditioned Relaxation				
Cognitive				
Facilitated Communication				
Higashi				
Holding Therapy				
Intensive Interaction				
Low Intrusion Teaching Methods				
Music Therapy				
Music Supported Communication				
Movement Communication Therapy				
Options				
Specific Diet				
Speech and Language Therapy				
TEACCH				
Other (please specify)				

## SECTION 3 - APPROACHES AT SCHOOL

(9) If your child currently attends preschool/school, please list any approaches used there with your child in the last 5 years, to the best of your knowledge (if not on the above list, a very brief description will suffice).

.....

## SECTION 4 - FUTURE APPROACHES

(10) Is your child likely to become involved in any approaches in the next 2-3 years?

Please tick any appropriate boxes and give relevant dates.

If they are not likely to become involved in any approaches please go to section 5.

APPROACH	AT PRESCHOOL /SCHOOL (✓)	OUTWITH PRESCHOOL /SCHOOL (✓)	EXPECTED START DATE MTH/YR (if known)	EXPECTED END DATE (if known)
Auditory Integration Training				
Augmented Communication (eg signs, pictures or symbols such as Makaton)				
Behaviour Modification (e.g. Lovaas)				
Cognitive				
Conditioned Relaxation				
Facilitated Communication				
Higashi				
Holding Therapy				
Intensive Interaction				
Low Intrusion Teaching Methods				
Music Therapy				
Music Supported Communication				
Movement Communication Therapy				
Options				
Specific Diet				
Speech and Language Therapy				
TEACCH				
Other (please specify)				

## SECTION 5 - FURTHER COMMENTS

(11) If you have any further comments regarding interventions for autism (e.g. any you have found to be particularly effective/ineffective) it would be very helpful to have these. Please write in the space below and continue on another sheet if need be.

THANK YOU FOR TAKING THE TIME TO FILL OUT THIS QUESTIONNAIRE!

## **APPENDIX C**

### **SON-RISE PROGRAM QUESTIONNAIRES (STUDY 2)**

#### **Questionnaires included:**

Questionnaire 1 – including cover letter.

Questionnaire 2

Questionnaire 3A – for parents who had implemented a SRP.

Questionnaire 3B – for parents who indicated in Q2 that they had not yet begun a SRP, but intended to in the future.

Questionnaire 3C – for parents who indicated in Q1 or Q2 that they did not intend to begin a SRP.

Questionnaire 3D – for non-respondents to Q1 and Q2.

## Questionnaire 1

### SON-RISE PROGRAM START-UP QUESTIONNAIRE FOR PARENTS/CARERS

Dear Parent/Carer

I am a PhD student at Moray House Institute of Education, University of Edinburgh, researching interventions for autism. I am focusing in particular on the Son-Rise Program as taught through the Option Institute. Permission to distribute this questionnaire was granted by the Option Institute, and it is designed to find out more about the type of children that the Son-Rise Program is currently being used with, and about the experiences of the families who are using the Son-Rise Program.

I understand that you have only just returned from the one week Start-Up Program and that it is unlikely that you have begun to implement a Son-Rise Program with your child. For this reason you may not yet have had a chance to think about some of the issues that are covered in this questionnaire. However, the aim of this questionnaire is to find out your thoughts and attitudes as a result of Start-Up course. Please do not feel that you are committed to stick to the type of Son-Rise Program which you describe in your answers to this questionnaire (e.g. number of hours you wish volunteers to work with your child for).

If you can take the time to fill out this questionnaire as fully as possible I would be very grateful. It should take about half an hour. However, if there are any questions you would prefer not to answer, please just leave them blank; equally, please feel free to be utterly honest in giving your opinions! Any personal information (e.g. names and addresses) provided in the returned questionnaires will be considered strictly confidential. Please return the questionnaire in the freepost envelope by the 15th August 1998. If you have any queries about my research feel free to contact me on 0131 558 6539.

Many Thanks,  
Katie Williams

### SECTION 1 - ABOUT YOU & THE START-UP PROGRAM

(1) How many children with special needs did you attend this course for? .....

If you attended this course for more than one child, please complete this for the eldest of the children. I will send you a questionnaire for your other child(ren) and if you could fill it in too I would be very grateful.

(2) Please state your relationship to the child .....

(3) Are you currently employed? *(circle as appropriate)*  
NO/ YES - FULL-TIME/ YES - PART-TIME

(4) If you have a spouse/partner are they currently employed? *(circle as appropriate)*  
NO/ YES - FULL-TIME/ YES - PART-TIME/ NOT APPLICABLE

### SECTION 2 - ABOUT THE CHILD

(1) Date of birth of child ...../...../..... (2) Sex of child M/F

(3) Does your child have brothers and sisters? *(please fill in and circle as appropriate)*

Age	Sex	Special Educational Needs? <i>(please describe)</i>
.....	M/F	.....
.....	M/F	.....
.....	M/F	.....
.....	M/F	.....

(4) Does your child have a specific primary diagnosis? *(please tick correct box)*

DIAGNOSIS	√	DIAGNOSIS	√
ADHD (attention deficit hyperactivity disorder)		Autism	
Asperger Syndrome		Autistic tendencies/features	
Awaiting Diagnosis <i>(if you know what the diagnosis is likely to be please specify)</i> .....		Other <i>(please specify)</i> ..... .....	

(5) Approximate age of child when diagnosed .....

(6) Has your child any learning difficulties or physical problems in addition to their diagnosis? **YES/NO/NOT YET ESTABLISHED***(circle as appropriate)*

If yes, please describe:

.....  
.....

(7) Are any other therapies/interventions (including medication or specific diet) currently being used with your child? **YES/NO** *(circle as appropriate)*

If yes, please specify:

.....  
.....

(8) Have any other therapies/interventions previously been used with your child ?  
**YES/NO** *(circle as appropriate)*

If yes, please specify:

.....  
.....

### **SECTION 3 - ABOUT THE SON-RISE PROGRAM & THE START-UP PROGRAM**

(1) How and when did you first hear about the Son-Rise Program?

.....  
.....

(2) What is it about the Son-Rise Program that attracted you to coming on this Start-Up?

.....  
.....

(3a) Do you plan to begin a Son-Rise Program with your child?

**YES/NO/UNSURE** *(circle as appropriate)*

(3b) Please give your reasons for your decision:

.....  
.....

**If you answered NO please go on to SECTION 6.**

#### SECTION 4 - YOUR SON-RISE PROGRAM

If you think at this time that you may, at some point in the future, create a Son-Rise Program for your child I'd be interested in knowing more of the specifics of what you might create, understanding that you may at any point choose to change these plans.

- (1) If you do plan on carrying out a Son-Rise Program with your child, or think that you might, please indicate:
  - (a) How many hours per week in total you would like to see the Son-Rise Program being used with your child for ..... hours
  - (b) Given your weekly schedule, how many hours per week you would like to work with your child, using the Son-Rise Program ..... hours

- (2) Have you, or do you think you will, create a Son-Rise playroom?  
YES/ NO/ UNSURE (please circle as appropriate)

- (3) If your child currently attends preschool/school, will he/she continue to attend if you begin a Son-Rise Program?  
(please tick correct box)

YES - child will continue to attend preschool/school	
NO - child will not continue to attend preschool/school	
Child will attend preschool/school part-time	
UNSURE	
Child does not currently attend preschool/school	

- (4) Will any other therapies/interventions (including medication and special diet) be used with your child after beginning a Son-Rise Program (either at school, if attending, or out of school) YES/NO/UNSURE (circle as appropriate)

If yes, please specify :

.....

- (5) If you do use the Son-Rise Program with your child what do you think you will prioritise as your first 3 main goals/aims for your child? (please be as specific as possible)

.....

.....

- (6) Overall how confident do you feel now about your ability to interact with your child using the Son-Rise Program? (please circle appropriate number)

Very Confident 1 2 3 4 5 Not At All Confident

- (7) If you've already worked in a Son-Rise room, or as you imagine doing so (using the techniques and attitudes of the Son-Rise Program) please rate your confidence levels for a one hour session with your child within the following areas:

(please tick correct box)	Very Confident	1	2	3	4	5	Not At All Confident
Joining in with your child's choice of activities/actions							
Choosing to accept your child's activities/behaviour							
Joining in with your child's 'isms' (stereotypic behaviour)							
Maintaining energy, enthusiasm and excitement							
Being 'present' (focusing your thoughts on a moment to moment basis)							
Choosing good moments for interaction within a session							
Being creative (ability to prioritise having fun and adding one new element to an activity a time)							
Choosing to feel comfortable with 'challenging' behaviour							

- (8) Which aspect of interacting with your child using the Son-Rise Program do you rate yourself, at this time, as most confident about? Please give reasons if possible. (use an aspect from the above list, or any other aspect)

.....  
 .....  
 .....

- (9) Which aspect of interacting with your child using the Son-Rise Program do you feel, at this time, you need more help/training input with ? Please give reasons if possible. (use an aspect from the above list, or any other aspect)

.....  
 .....  
 .....

- (10) Understanding that you may not have set up a Son-Rise Program and that you may not have had experience of using all that you've learnt, are there any aspects of the Son-Rise Program that you think you will choose not to implement due to your own special circumstance? YES/NO/UNSURE (circle as appropriate)

If YES please specify, and give reasons if possible:

.....  
 .....

#### **SECTION 5 - VOLUNTEERS**

- (1) How many volunteers in total would you like to work with your child? .....
- (2) How many hours per week will you ask each volunteer to work with your child for? ..... hours

- (3) Overall how confident do you feel about your ability to organise the running of a Son-Rise programme? (please circle appropriate number)

Very Confident 1      2      3      4      5      Not At All Confident

#### **SECTION 6 - FOLLOW-UP**

I would like to send as many families as possible a follow-up questionnaire in 6- 12 months time. If you would be willing to complete a follow-up questionnaire, please write your name and address below:

Name .....

Address .....

.....

.....

.....

Postcode .....

#### **SECTION 7 - ADDITIONAL COMMENTS**

- (1) Do you have any additional comments? If so, please write them in the space below.

.....  
 .....  
 .....

THANK YOU FOR TAKING THE TIME TO FILL OUT THIS QUESTIONNAIRE !



Questionnaire 2

SECTION 1 - ABOUT YOU & YOUR CHILD

- (1) Your Name .....  
Address .....  
.....
- (2) Has your employment status (e.g. full-time, part-time, not working) changed since the last questionnaire (July 1998)? Yes/No (Please delete as appropriate)  
If 'yes' please specify .....
- (3) Has your partner's employment status changed since the last questionnaire?  
Yes/No (Please delete as appropriate)  
If 'yes' please specify .....
- (4) If your child was not previously diagnosed at the time of the last questionnaire, or has since been given an additional diagnosis please give it here:  
.....

SECTION 2 - SON-RISE PROGRAM

- (1) Have you set up a Son-Rise program for you child?  
(please tick appropriate box) ✓
- |  |  |
|--|--|
| Yes - Son-Rise Program began on ...../..... (M/Y) (please give date) |  |
| No - but intend to begin in the future                               |  |
| No - no longer intend to use a Son-Rise Program                      |  |

- (2) If you have not yet begun a Program, or no longer intend to begin one, please could you indicate the circumstances which led to this (e.g. another intervention is being used with the child instead, work and family commitments make running a Son-Rise Program impossible etc.)  
.....  
.....  
If you have not set up a Son-Rise Program, and do not intend to, please go to Section 7.
- If you have set up a Son-Rise Program for your child, even if it is no longer running, please go to question 3. (If the latter please answer the questions in relation to the period you used it).
- (3) Have you set up a Son-Rise Playroom for your child?  
Yes/No (Please delete as appropriate)
- (4) Currently, how many hours per week in total is the Son-Rise Program used with your child for (on average)? ..... hrs
- (5) Currently, how many hours per week do you personally work with your child using the Son-Rise Program? ..... hrs

- (6) Has your child continued to attend preschool/school while involved in the Son-Rise Program?

(please tick appropriate box)

√

Yes - child continues to attend preschool/school (please delete as appropriate)	<input type="checkbox"/>
No - child does not continue to attend preschool/school (please delete as appropriate)	<input type="checkbox"/>
Child attends preschool/school (please delete as appropriate) part-time	<input type="checkbox"/>
Child did not attend preschool/school before beginning Son-Rise Program	<input type="checkbox"/>

- (7) Please describe what influenced your decision to continue/discontinue your child's attendance at preschool/school:

.....

.....

.....

.....

.....

- (8) Are any other therapies/interventions (including medication and special diet) also being used with your child (either at school, if attending, or out of school)?

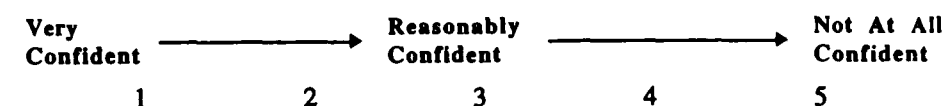
Yes/No (please delete as appropriate)

If yes, please specify:

.....

.....

- (9) Overall, how confident do you feel now about your ability to interact with your child using the Son-Rise Program? (please circle appropriate number)



- (10) When working in a Son-Rise room (using the techniques and attitudes of the Son-Rise Program) please rate your confidence levels for a one hour session with your child within the following areas :

(please tick appropriate box)

	Very Confident	1	2	3	4	5	Not At All Confident
Following your child's choice of activities/actions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Choosing to accept your child's activities/behaviour	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Joining in with child's 'isms' (stereotypic behaviour)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Maintaining energy, enthusiasm and excitement	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Being 'present' (focusing your thoughts on a moment to moment basis)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Choosing good moments for interaction within a session	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Being creative (ability to prioritise having fun and adding one new element to an activity at a time).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Choosing to feel comfortable with 'challenging' behaviour	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

- (11) Which aspect of interacting with your child using the Son-Rise Program are you currently most confident about? Please give reasons if possible (use an aspect from the above list, or any other you think important/relevant).

.....

.....

.....

- (12) Which aspect of interacting with your child using the Son-Rise Program do you currently feel you need more help/training with? Please give reasons if possible (again use an aspect from the above list or any other important/relevant one).

.....  
 .....  
 .....

- (13) When working with your child using the Son-Rise Program, how confident do you feel that you are 'going in the right direction' with your child (e.g. how confident do you feel about knowing what to do next, knowing whether you are challenging your child too much/too little etc.)? *(please circle appropriate number)*

Very Confident      Reasonably Confident      Not At All Confident

1                      2                      3                      4                      5

### SECTION 3 - VOLUNTEERS

- (1) a. How many volunteers currently work with your child each week? .....
- (1) b. If you currently have no volunteers working with your child please say why (e.g. don't feel ready yet for volunteers, don't want strangers in the house, problems with recruiting volunteers etc.)

.....  
 .....  
 .....

**If you currently have no volunteers please go now to section 4.**

- (2) Currently, what is the least and most number of hours per week that any individual volunteer works with your child for? .....hrs - .....hrs  
*(least) - (most)*

- (3) a. Do you continue to give your volunteers feedback on their technique once they have had their initial training? **Yes/No** *(Please delete as appropriate)*

- (3) b. If 'yes' please specify how often you give feedback on average :  
**Weekly/Fortnightly/Monthly/Less often** *(Please delete as appropriate)*

- (4) What has been your experience of giving volunteers feedback? (e.g. have you felt confident about giving feedback, do you feel that some volunteers don't implement the suggestions from your feedback, Have there been changes over time in how easy/difficult you find giving feedback etc.)

.....  
 .....  
 .....  
 .....  
 .....

- (5) a. Do you hold meetings for your volunteers? **Yes/No** *(Please delete as appropriate)*

- (5) b. If 'yes' please specify how often you hold meetings on average :  
**Weekly/Fortnightly/Monthly/Less Often** *(Please delete as appropriate)*

- (6) Would you like to hold meetings more often?

*(please tick appropriate box)*

Yes - but I don't have enough time	✓
Yes - but volunteers don't have enough time	
Yes - please specify any other reasons	
.....	
No - am happy with how often I hold meetings	

(7) Overall how easy/difficult have you found the following:

(Please tick appropriate box, leaving blank any of which you have not had experience of)

Very Easy → Very Difficult

	1	2	3	4	5
Getting enough volunteers					
Getting reliable volunteers					
Getting volunteers who can work well in the playroom					
Getting volunteers to work the number of hours you wish					
Training volunteers					
Giving volunteers constructive feedback					
Running constructive meetings for your volunteer team					

(8) Overall how confident do you feel about your ability to organise the running of your Son-Rise Program? (please circle appropriate number)

Very Confident 1      2      3      4      5 Not At All Confident

(9) If you have any further comments to make about your experience of working with volunteers (e.g. how you feel about running meetings, whether you have kept the same team of volunteers for the whole programme or if this has changed, how your child has reacted to volunteers etc.) please write them in the space below:

.....

.....

.....

.....

#### SECTION 4 - YOUR CHILD

(1) Please give examples of the sort of progress, if any, that you feel your child has made during the time of your Son-Rise Program (areas to consider include language, social interaction, toilet training, eye contact, isms/repetitive routines, play skills, attention, challenging behaviour and academic skills.)

.....

.....

.....

.....

(2) Please indicate any areas of your child's development where progress has been less than you would have hoped for:

.....

.....

.....

.....

#### SECTION 5 - YOU AND YOUR FAMILY

(1) Do you feel that running the Son-Rise Program has had an impact on the rest of your family (e.g. your relationships with them, quantity/quality of time spent with them)? If so, please indicate how:

.....

.....

.....

.....

## SECTION 6 - ENDING OF SON-RISE PROGRAM

(1) Is your Son-Rise program still running?

Yes/No (please delete as appropriate)

(2) a. If your Son-Rise program is no longer running, please say when it ended.

...../..... (M/Y) (please give date)

(2) b. Please give your reasons for ending your Son-Rise Program:

.....  
.....  
.....

## SECTION 7 - SUPPORT FROM THE OPTION INSTITUTE

(If you have not started or do not intend to start a Son-Rise Program please still complete as many parts of this section as possible as the information will be very useful for this research.)

(1) Have you booked to attend any of the following Son-Rise training programs?

Advanced Son-Rise Training at Option Institute Yes/No (please delete as appropriate)

- If 'yes' please give the date you will attend ...../..... (M/Y)

Intensive Course at Option Institute

Yes/No (please delete as appropriate)

- If 'yes' please give the date you will attend ...../..... (M/Y)

(2) a. Please indicate how many times you have made use of the following Son-Rise support services offered by the Option Institute and Fellowship :

(Please put the appropriate number in the box )

Phone consultation

Phone Dialogue

Feedback on a video of you/your volunteers working with your child

Feedback on a video/audio cassette of you giving your volunteers feedback

Outreach visit by member of Option staff

(2)b. Please give a summary of the reasons why you did or did not use these support services (e.g. not sure that I was implementing the techniques correctly, thought the cost of the telephone calls might be prohibitive etc.)

.....  
.....

(3) How well do you feel that the initial Start-Up course in London prepared you for using a Son-Rise Program with your child: (Please circle appropriate number)

Very Well —————> Sufficiently —————> Not At All Well  
1 2 3 4 5

(4) If you have any further comments to make about the training/support you have received from the Option Institute, please write them in the space below:

.....  
.....  
.....

**SECTION 8 - FURTHER COMMENTS**

- (1) If you have any further comments about your experience of the Son-Rise Program to date, please write them in the space below:

.....  
.....  
.....

**THANK YOU FOR TAKING THE TIME TO FILL IN THIS QUESTIONNAIRE !**

## Questionnaire 3A - For parents who had Implemented a SRP

### SECTION 1 - ABOUT YOU & YOUR CHILD

(1) Has your employment status (e.g. full-time, part-time, not working) changed since the last questionnaire (Feb 1999)? **Yes/No** (please delete as appropriate) If 'yes' please specify .....

(2) Has your partner's employment status changed since the last questionnaire ? **Yes/No**  
If 'yes' please specify .....

(3) If you or your partner's employment status has changed at all since the Start-Up course, were these changes related to your Son-Rise Program? **Yes/No**

If 'yes', please explain in what way they were related:

.....  
.....

(4) If your child was not previously diagnosed at the time of the last questionnaire, or has since been given an additional diagnosis, please give it here:

.....

### SECTION 2 - YOUR SON-RISE PROGRAM

(1) Is your Son-Rise Program still running? **Yes/No**

(2)a. If your Son-Rise Program is no longer running, please say when it ended:  
...../..... (month/year)

(2)b. Please give your reasons for ending your Son-Rise Program (e.g. progress of child meant that intervention no longer required, did not feel confident about working with child, difficulties recruiting volunteers).

.....  
.....  
.....

**Please answer the following questions. They relate to your current use of the Son-Rise Program. If your Son-Rise Program is no longer running, please answer them in relation to the period you used it.**

(3) How many hours per week do you personally work with your child using the Son-Rise Program ? ..... hrs

(4) How many hours per week in total is the Son-Rise Program used with your child (on average) ? ..... hrs

(5)a. How do you feel about the number of hours the Son-Rise Program is used with your child for each week?

÷ (please tick appropriate box)

<input type="checkbox"/>	The number of hours is sufficient
<input type="checkbox"/>	I would like the Program to be used with my child for <b>fewer</b> hours each week
<input type="checkbox"/>	I would like the Program to be used with my child for <b>more</b> hours each week

(5)b. If you would like the Program to be used with your child for **more** hours each week, please specify the reasons why you are currently unable to do so (e.g. lack of volunteers, lack of energy, work commitments).

.....  
.....  
.....  
.....

(6)a. Is your child currently attending preschool/school?

✓ (please tick appropriate box)

<input type="checkbox"/>	Yes - child currently attends preschool/school (please delete as appropriate)
<input type="checkbox"/>	No - child does not currently attend preschool/school (please delete as appropriate)
<input type="checkbox"/>	Child attends preschool/school part-time (please delete as appropriate)
<input type="checkbox"/>	Child did not attend preschool/school before beginning the Son-Rise Program and still doesn't

(6)b. If your child's attendance is part-time, please indicate how many hours per week they spend at preschool/school. .... hours

(7) If your child's school attendance has changed since the last questionnaire (e.g. previously attended school, now does not) please describe the reasons for this :

.....

.....

.....

(8) Are any other therapies/interventions (including medication and special diet) also being used with your child at present (either at school or out of school)?

Yes/No

If yes, please specify :

.....

.....

(9) Overall, how confident do you feel now about your ability to interact with your child using the Son-Rise Program? (please circle appropriate number)

Very Confident	→	Reasonably Confident	→	Not At All Confident
1		2		3
				4
				5

(10) When working in a Son-Rise room (using the techniques and attitudes of the Son-Rise Program) please rate your current confidence levels for a one hour session with your child within the following areas :

(please tick appropriate box, leaving blank any which do not apply to your child)

	Very Confident	1	2	3	4	5	Not At All Confident
Joining in with your child's choice of activities/actions							
Choosing to accept your child's activities/behaviour							
Joining in with child's 'isms' (stereotypic behaviour)							
Maintaining energy, enthusiasm and excitement							
Being 'present' (focusing your thoughts on a moment to moment basis)							
Choosing good moments for interaction within a session							
Being creative (ability to prioritise having fun and adding one new element to an activity at a time).							
Choosing to feel comfortable with 'challenging' behaviour							

(11) Which aspect of interacting with your child using the Son-Rise Program are you currently most confident about? Please give reasons if possible (use an aspect from the above list, or any other you think important/relevant).

.....

.....

(12) Which aspect of interacting with your child using the Son-Rise Program do you currently feel you need more help/training with? Please give reasons if possible (again, use an aspect from the above list or any other important/relevant one).

.....

.....



- (13) When working with your child using the Son-Rise Program, how confident do you now feel that you are 'going in the right direction' with your child (e.g. how confident do you feel about knowing what to do next, knowing whether you are challenging your child too much/too little etc.) ? *(please circle appropriate number)*

Very Confident  $\longrightarrow$  Reasonably Confident  $\longrightarrow$  Not At All Confident

1 2 3 4 5

### SECTION 3 - VOLUNTEERS

- (1)a. How many volunteers currently work with your child each week? .....
- (1)b. If you have no volunteers working with your child, please could you indicate the reasons for this:

$\div$  *(please tick all boxes that apply)*

<input type="checkbox"/>	Want to feel confident in use of techniques before training volunteers
<input type="checkbox"/>	Living in a remote area makes recruitment of volunteers difficult
<input type="checkbox"/>	Poor response to publicity advertising for volunteers
<input type="checkbox"/>	Lack of spare time to spend recruiting volunteers
<input type="checkbox"/>	Difficulties in keeping volunteers once they have been recruited
<input type="checkbox"/>	Do not need volunteers as family can cover the hours
<input type="checkbox"/>	Wary of having strangers in the house
<input type="checkbox"/>	Other reasons <i>(please specify)</i> :.....

- (1)c. If you ticked more than one reason above, which **one** was the most important?

.....

**IF YOU HAVE NO VOLUNTEERS PLEASE GO NOW TO SECTION 4.**

- (2) What is the minimum and maximum number of hours per week that any individual volunteer works with your child for? .....hrs - .....hrs
- (least) - (most)*

- (3)a. Are you currently giving volunteers feedback on their technique once they have had their initial training ? **Yes/No**

- (3)b. If 'yes', please specify how often you currently give feedback on average:  
**Weekly/Fortnightly/Monthly/Less often** *(please delete as appropriate)*

- (4)a. Do you receive feedback from anyone on your own technique? **Yes/No**

- (4)b. If 'yes', please specify how often you currently receive feedback on average:  
**Weekly/Fortnightly/Monthly/Less often** *(please delete as appropriate)*

- (4)c. If 'yes', please specify who gives you feedback (e.g. partner, volunteer, Son-Rise staff) .....

- (5)a. Do you currently hold meetings for your volunteers? **Yes/No**

- (5)b. If 'yes', please specify how often you hold meetings on average:  
**Weekly/Fortnightly/Monthly/Less Often** *(please delete as appropriate)*

- (6) Overall, how easy/difficult are you finding the following :

*(please tick appropriate box, leaving blank any of which you have no experience)*

Very Easy  $\longrightarrow$  Very Difficult

	1	2	3	4	5
Getting enough volunteers					
Getting reliable volunteers					
Getting volunteers who can work well in the playroom					
Getting volunteers to work the number of hours you wish					
Training volunteers					
Giving volunteers constructive feedback					
Running useful meetings for your volunteer team					

- (7) Overall how confident do you currently feel about your ability to organise the running of your Son-Rise Program ? *(please circle appropriate number)*

Very Confident      Reasonably Confident      Not At All Confident

1                      2                      3                      4                      5

- (8) If you have any further comments about your experience of working with volunteers to date, please write them in the space below:

.....

.....

.....

.....

#### SECTION 4 - YOUR CHILD

- (1) Please give examples of the sort of progress, if any, that you feel your child has made since the last questionnaire in Feb 1999 (areas to consider include language, social interaction, toilet training, eye contact, 'isms'/repetitive routines, play skills, attention, challenging behaviour and academic skills).

.....

.....

.....

.....

- (2) If you feel that your child has made progress through the Son-Rise Program in more than one developmental area, in which **one area** has your child made most progress?

.....

- (3)a. Please indicate any areas of your child's development where progress has been less than you would have hoped for, since the last questionnaire (Feb 1999):

.....

.....

.....

.....

- (3)b. Why do you think this is?

.....

.....

.....

- (4) Overall which sentence best describes the outcome for your child of using Son-Rise Program?

÷ *(please tick appropriate box)*

<input type="checkbox"/>	Little or no effect
<input type="checkbox"/>	Minor but constant progress throughout
<input type="checkbox"/>	Intermittent spurts of minor progress
<input type="checkbox"/>	Intermittent spurts of substantial progress
<input type="checkbox"/>	Initially substantial progress, followed by minor progress
<input type="checkbox"/>	Initially minore progress, followed by substantial progress
<input type="checkbox"/>	Constant substantial progress throughout
<input type="checkbox"/>	Other (please specify).....

(5)a. Overall how beneficial would you say Son-Rise has been for your child?

(Please tick appropriate box)

Not at all beneficial	Slightly beneficial	Moderately beneficial	Very beneficial

(5)b. If you ticked 'moderately beneficial', 'slightly beneficial' or 'not at all beneficial' for question 3, do you think the Son-Rise Program was less effective than you might have hoped because of:

+ (please tick all boxes which apply)

	The number of hours you used the Son-Rise Program for each week
	Your particular family circumstances
	The suitability of the Son-Rise Program for the age of your child
	The suitability of the Son-Rise Program for your child's specific diagnosis
	Your ability to use the techniques/attitude of the Son-Rise Program
	Other (please specify)
	.....
	.....

## SECTION 5 - YOU AND YOUR FAMILY

(1) Do you feel that running the Son-Rise Program currently has an impact on the rest of your family (e.g. your relationships with them, quantity/quality of time spent with them)? If so, please describe how:

.....

.....

.....

.....

.....

.....

(2)a. Please tick the box which best describes how your family life has been since beginning your Son-Rise Program:

(please tick appropriate box)

A great deal more stressful	Slightly more stressful	Has stayed the same	Slightly less stressful	A great deal less stressful

(2)b. Please tick the box which best describes how your family life has been since beginning your Son-Rise Program:

(please tick appropriate box)

A great deal happier	Slightly happier	Has stayed the same	Slightly less happy	A great deal less happy

## SECTION 7 - SUPPORT FROM THE OPTION INSTITUTE

- (1) Did you attend the Maximum Impact Training in London in July 1999?

Yes/No

If yes, please describe your experience of this course:

.....

.....

.....

- (2) Please indicate how many times **since the Start-Up course** you have now made use of the following support services offered by the Option Institute:

*(please insert relevant number of times in the box )*

- ☐ Phone consultation
- ☐ Phone dialogue
- ☐ Feedback on a video of you/your volunteers working with your child
- ☐ Feedback on a video/audio tape of you giving your volunteers feedback
- ☐ Outreach visit by member of Option staff (including staff based in UK)

- (3) If you have any further comments about the training/support you have received from the Option Institute to date, please write them in the space below:

.....

.....

.....

## SECTION 8 - FUNDRAISING

- (1) Did you, or other people, fundraise for your Son-Rise Program?

÷ *(please tick all appropriate boxes)*

<input type="checkbox"/>	No - we did not fundraise
<input type="checkbox"/>	Yes - the immediate family was involved in fundraising
<input type="checkbox"/>	Yes - other people were involved in fundraising

- (2) Overall, how would you describe the financial effects, if any, of the Son-Rise Program on you and your family?

*(please tick appropriate box)*

None	Slight	Moderate	Severe
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## SECTION 9 - FURTHER COMMENTS

- (1) If you have any further comments about your experience of the Son-Rise Program to date, please write them in the space below :

.....

.....

.....

.....

**THANK YOU FOR TAKING THE TIME TO FILL IN THIS QUESTIONNAIRE !**

**Questionnaire 3B - Sent to parents who indicated in Q2 that they had not yet begun a SRP, but intended to in the future**

(1) Have you set up a Son-Rise Program for your child?

√ (please tick appropriate box)

<input type="checkbox"/>	Yes - Son-Rise Program began on ...../..... (month/year)
<input type="checkbox"/>	No - but intend to begin in the future
<input type="checkbox"/>	No - no longer intend to use a Son-Rise Program

**IF YOU HAVE BEGUN A PROGRAM FOR YOUR CHILD, PLEASE GO TO QUESTIONNAIRE A - SECTION 1 ON NEXT PAGE**

(2)a. If you have **not** yet begun a Program, or no longer intend to begin one, please could you indicate the circumstances which led to this:

÷ (please tick all boxes that apply)

<input type="checkbox"/>	Difficulties in setting up a playroom
<input type="checkbox"/>	Financial reasons
<input type="checkbox"/>	Work commitments
<input type="checkbox"/>	Family commitments
<input type="checkbox"/>	Did not feel confident using the techniques/attitude of the Son-Rise Program
<input type="checkbox"/>	Difficulty in recruiting volunteers
<input type="checkbox"/>	Felt that Son-Rise Program was not suitable for your particular child
<input type="checkbox"/>	Decided to use another intervention instead
<input type="checkbox"/>	Other reason (please specify) .....

(2)b. If you ticked more than one reason above, which **one** was the most important in your decision to begin your Program at a later date/not to use a Program?

.....

(3)a. As a result of the Start-Up course did interactions with your child:

☐ stay much the same      ☐ change      (please tick appropriate box)

(3)b. If interactions with your child changed, please specify how:

.....  
.....

(please continue on back of sheet if need be)

(4) Are any other therapies/interventions (including medication and special diet) being used with your child at present (either at school, or out of school)?

Yes/No (please delete as appropriate)

If yes, please specify:

.....  
.....

**THANK YOU FOR TAKING THE TIME TO FILL IN THIS QUESTIONNAIRE!**  
(There is no need to bother with the following pages; please just return this page in the SAE provided)

**Questionnaire 3C – Sent to parents who indicated in Q1 or Q2 that they did not intend to begin a SRP**

- (1)a. In a previous questionnaire you indicated that you did not intend to use a Son-Rise Program with your child. As it is important to clarify the position of all families in this study one year after the Start-Up course, could you please indicate your current situation:

÷ (Please tick appropriate box)

<input type="checkbox"/>	I have not begun a Son-Rise Program and do not intend to in the future
<input type="checkbox"/>	I intend to use a Son-Rise Program with my child in the future
<input type="checkbox"/>	I began a Son-Rise Program on ...../..... (month/year)

- (1)b. If you are now running a Son-Rise Program would you be willing to complete a further brief questionnaire? **Yes/No** (Please delete as applicable)

- (2) In a previous questionnaire you mentioned some reasons why you intended not to use a Son-Rise Program. In order to gain more details on why families feel that the Son-Rise Program is not suited to their child/family circumstances I would be grateful if you could indicate if any of the reasons listed below contributed to your decision:

÷ (Please tick all boxes that apply)

<input type="checkbox"/>	Difficulties in setting up a playroom
<input type="checkbox"/>	Financial reasons
<input type="checkbox"/>	Work commitments
<input type="checkbox"/>	Family commitments
<input type="checkbox"/>	Did not feel confident using the techniques/attitude of the Son-Rise Program
<input type="checkbox"/>	Difficulty in recruiting volunteers
<input type="checkbox"/>	Felt that Son-Rise Program was not suitable for your particular child
<input type="checkbox"/>	Decided to use another intervention instead
<input type="checkbox"/>	Other reasons (please specify).....

- (2)b. If you ticked more than one reason above, which **one** was the most important in your decision not to use a Program?

- (3) Are any other therapies/interventions (including medication and special diet) currently being used with your child (either at school, if attending, or out of school)?

**Yes/No**

If yes, please specify:

- (4)a. Please give examples of the sort of progress, if any, that you feel your child has made since July 1998 (areas to consider include language, social interaction, toilet training, eye contact, 'isms'/repetitive routines, play skills, attention, challenging behaviour and academic skills.)

(4)b. If you feel that your child has made progress in more than one developmental area, in which one area has your child made most progress?

.....

(5)a. Please indicate any areas of your child's development where progress has been less than you would have hoped for since July 1998:

.....

.....

.....

.....

.....

(5)b. Why do you think this is?

.....

.....

(6)a. Following the Start-Up course did interactions with your child:

☐ stay much the same      ☐ change (please tick appropriate box)

(6)b. If interactions with your child did change, please specify how:

.....

.....

.....

.....

(7) If you have any further comments about your experience of the Son-Rise Program, or your child's progress over the past year please write them on the following blank sheet.

THANK YOU FOR TAKING THE TIME TO FILL IN THIS QUESTIONNAIRE!

### Questionnaire 3D – For non-respondents to Q1 and Q2

(1) Have you set up a Son-Rise Program for your child?

√ (please tick appropriate box)

<input type="checkbox"/>	Yes - Son-Rise Program began on ...../..... (month/year)
<input type="checkbox"/>	No - but intend to begin in the future
<input type="checkbox"/>	No - no longer intend to use a Son-Rise Program

(2)a. If you have **not** yet begun a Program, or no longer intend to begin one, please could you indicate the circumstances which led to this:

÷ (Please tick all boxes that apply)

<input type="checkbox"/>	Difficulties in setting up a playroom
<input type="checkbox"/>	Financial reasons
<input type="checkbox"/>	Work commitments
<input type="checkbox"/>	Family commitments
<input type="checkbox"/>	Did not feel confident using the techniques/attitude of the Son-Rise Program
<input type="checkbox"/>	Difficulty in recruiting volunteers
<input type="checkbox"/>	Felt that Son-Rise Program was not suitable for my particular child
<input type="checkbox"/>	Decided to use another intervention instead
<input type="checkbox"/>	Other reason (please specify).....
<input type="checkbox"/>	.....

(2)b. If you ticked more than one reason above, which **one** was the most important in your decision to begin your Program in the future/not to use a Program?

.....

(3) If you **are** running a Son-Rise Program, how many hours per week **in total** is it currently being used with your child for (on average)? ..... hrs

(4) If you **are** running a Son-Rise Program, has your child continued to attend preschool/school?

√ (please tick appropriate box)

<input type="checkbox"/>	Yes - child continues to attend preschool/school (please delete as appropriate)
<input type="checkbox"/>	No - child does not currently attend preschool/school (please delete as appropriate)
<input type="checkbox"/>	Child attends preschool/school part-time (please delete as appropriate)
<input type="checkbox"/>	Child did not attend preschool/school before beginning Son-Rise, and still doesn't

(5) Would you be willing to complete a further questionnaire about you and your child's experiences over the past year? **Yes/No**

(6) If you have any further comments about your experience of the Son-Rise Program to date, please write them on the back of this sheet.

**THANK YOU FOR TAKING THE TIME TO FILL IN THIS QUESTIONNAIRE !**



## APPENDIX D

### SON-RISE PROGRAM INTERVIEW SCHEDULES (STUDY 3)

#### Points discussed with parents before each interview

- (1) The aim of the interviews is to explore the experiences of families using the SRP - questions are not intended to be in any way judgmental.
- (2) No right and wrong answers - just give your own opinions on the topics.
- (3) Please say if there are any questions you would prefer not to answer. Equally please feel free to be utterly honest in giving your opinions.
- (4) Feel free to switch off the tape at any time if you would like to say something that you would prefer not to be taped.
- (5) At some points I may stop you and move on to the next topic. Please do not take this as an indication that I'm not interested in what you are saying. It is just because there are several topics to cover in the hour, and it is important that we cover all of them.
- (6) You can end the interview at any time you wish.

#### Interview 1 schedule

##### (1) *Start-Up Course*

- (a) Tell me a bit about why you decided to attend the SRP Start-Up course.

*Prompt* - what had made you interested in finding out more about the SRP?

*Prompt* - were there any aspects of the SRP which particularly attracted you, or that you were less keen on before you attended?

- (b) Tell me a bit about how you found the Start-Up course.

*Prompt* - tell me about the teaching methods.

*Prompt* - tell me about your feelings during the week about the teaching

*Prompt* - tell me about your feelings during the week about the atmosphere of the course

- (c) Did you feel that the course covered all the aspects you wanted it to?

*Prompt* - were there any aspects of the approach that you found particularly appealing or any you found less appealing during the week?

- (d) Did you find the course gave value for money?

- (e) Roughly when do you plan to begin your SRP or when did it begin?

##### (2) *Child*

- (a) What do you think your child's reaction will be/has been to the SRP?

*Prompt* - how do you think he will react to the techniques and attitudes?

- (b) What do you think your child's reaction will be to being in the room? Or what has your child's reaction been to being in the room? (if applicable)

*Prompt* - do you think your child will enjoy being in the room, or will he/she not be keen?

*Prompt* - what are your feelings about your child's reaction?

- (c) Tell me a bit about how you hope your child will change as a result of the SRP.

*Prompt* - (if can't think of any) perhaps you could think of changes in one or more of the following areas - social, communication, play, motor or education skills.

- (d) Why have you chosen these goals as the one's that are important to you?

##### (3) *Family*

- (a) What do you think the effects, if any, will be of the SRP on the rest of the family? Or have been effects already.

*Prompts* - how about on your spouse/partner?

*Prompt* - how about your other children?

- (b) What have been the views of your other relatives and friends about the SRP?

*Prompt* - how have the views of other people affected you and your program, if at all?

#### **(4) Schooling/Professional Advice**

(a) (If child is at school) Could you tell me a bit about your child's school?

*Prompt* - is it a mainstream school, or a special school, or a pre-school?

*Prompt* - whose choice was it to put him/her in that particular school?

(b) Will your child continue to attend school? If so, why? If not, why not?

*Prompt* - how do you think your SRP will fit in or not fit in with your child's schooling?

*Prompt* - does the school have a similar or different ethos to the SRP?

(c) What have been the views of the school about you choosing the SRP?

*Prompt* - how about your child's teachers?

*Prompt* - how have the views of the school affected you and your program, if at all?

(d) What have been the views of other professionals about you choosing the SRP?

*Prompt* - how about your child's G.P., psychologist, and other therapists?

*Prompt* - how have the views of these people affected you and your program, if at all?

#### **(5) Other therapies**

(a) Will you use other interventions, including medication and diet, and other therapies? Tell me a bit about how you think these will or will not fit in with the SRP.

*Prompt* - (if not sure if other therapies will fit or not) will the therapy follow any of the same ideas as the SRP or does it follow quite different ideas?

(b) Why did you choose to use other therapies/ to not use other therapies?

#### **(6) Yourself**

(a) Tell me a bit about how you yourself feel about working in the room with your child.

*Prompt* - are there any aspects of working in the room that you feel particularly confident/not confident about or that you particularly like/dislike? Why is this?

(b) Tell me a bit about your relationship with your child since the Start-Up course.

*Prompt* - has it changed or has it stayed the same?

(c) What do you think the effects, if any, of the SRP will be on you, or have already been?

*Prompt* - have you changed or has it not had much impact on you?

(d) Could you talk a little bit about finding time for yourself?

#### **(7) Theory to Practice**

(a) Overall how closely do you think you will follow the way the Option Institute say you should carry out a program? Firstly if we discuss within the room.

*Prompt* - are there any aspects you will either emphasise or not use and if so why?

(b) Secondly if we discuss aspects outwith the room.

*Prompt* - such as your child going outside, or volunteers, meetings and feedback.

#### **(8) Volunteers**

(a) If you could talk a little bit now about volunteers.

(b) What are your feelings about recruiting and initial training?

#### **(9) Fundraising**

Do you plan to fundraise for your SRP, or do you not think this will be necessary?

*Prompt* - (if no) why is that?

*Prompt* (if yes) how do you think that this will fit in with running your program?

*Prompt* - what will you prioritise the money for?

#### **Finishing comments to parent after each interview**

(1) Is there anything else you would like to add which you feel I haven't covered?

(2) Is there anything that you would like to ask me?

(4) Is there any comment they made which, on reflection, they would prefer not to have been taped? These comments can be removed from the transcription of the interview.

(5) Did any questions upset you/make you feel uncomfortable?

(6) What was your opinion of the interview - did you feel there were topics that you would've liked to have covered in more depth/less depth or in a different way?

## **Interview 2 schedule**

### **(1) Your child & your program**

(a) How long has your program been running for now?

(b) How has your child reacted to the SRP and to being in the playroom?

*Prompt* - how has s/he reacted to the techniques/ being in the room?

- what are your feelings about his/her reactions?

(c) Can you give examples of the sort of progress, if any, that you feel your child has made during your SRP?

*Prompt* - how about in other areas such as language, social interaction, toilet training, eye contact, attention, academic skills?

(d) To what extent would you attribute this progress to the SRP?

(e) Could you tell me about any areas of your child's development where progress has been less than you would have hoped for?

*Prompt* - how about in other areas such as language, social interaction, toilet training, eye contact, attention, academic skills?

*Prompt* - why do you think that is?

(f) Roughly how many hours do you do each week?

(g) How do you feel now about your decision to take your child out of the house?

### **(2) You**

(a) How have you found working in the room with your child since you began your SRP?

*Prompt* - have there been aspects you particularly liked or disliked using, or that you felt particularly confident or not confident about? Why is that?

(b) How confident have you felt that you have been 'going in the right direction'? What I mean by that is how confident have you been that you have been choosing the correct goals to focus on, that you have been challenging your child enough, but not too much etc.

(c) Do you feel pressure to 'get results' or 'do well' with the program, or not really? If so, where does this pressure come from?

(d) (where applicable) At the beginning of your program you decided to take leave/give up work/stay at work, how do you feel now about that decision?

(e) To what extent, if at all, do you apply SRP attitudes to other areas of your life?

### **(3) Family**

(a) Could you tell me a little bit about what the effects, if any, have been of the SRP on your family?

*Prompt* - how about on your husband/other children?

*Prompt* - how do you feel about that?

(b) Is your husband involved in the running of your SRP?

### **(4) Volunteers**

(a) What has been your experience of using volunteers?

*Prompt* - how about recruiting/ giving feedback/ having meetings?

- how about the number of hours they work for each week?

(b) How has your child reacted to the volunteers?

### **(5) Support from Option Institute**

(a) Looking back, do you feel that the Start-Up course prepared you well for running the SRP, or do you feel that it prepared you well in some ways but not others?

(b) Have you used the follow-up support available and if so how did you find it?

(c) What are your feelings about the Maximum Impact Advanced training and the Intensive?

### **(6) Schooling**

(a) After the SRP you made a decision about schooling (i.e. whether to continue, continue part-time or discontinue). How do you feel now about that decision?

(b) (If child is at school) how is the SRP fitting in with your child's schooling?

*Prompt* - do the school show an interest in what goes on with your SRP? If so, in what way?

**(7) Other therapies**

(a) Are you considering other therapies or are you happy with the way things are going?

*Prompt* - (if yes) what attracts you to that therapy?

**(8) Fundraising**

(a) (For those who have been involved in some kind of fundraising) what has been your experience of fundraising, or having others fundraise for you?

(b) What has been your experience of the financial side of running a SRP?

**(9) Overall**

(a) How do you feel now about your decision to undertake a SRP?

(b) How would you sum up your experiences of your SRP so far?

**Interview 2 schedule (for family no longer running SRP)**

**(1) Decision not to run a program**

What do you think were the most important factors affecting your decision not to use a SRP?

*Prompts* - Do you think...(below) was relevant/came into it at all?

(a) Your child's school or education

(b) Your family

*Prompt* - what were your husband's feelings about the SRP?

*Prompt* - did you think it would have any effect on the other children?

(c) Your job

(d) How suitable the SRP seemed to be for your particular child

(e) Your own feelings about interacting with your child using the techniques of the SRP

(f) Your own feelings about running a SRP, e.g. recruiting volunteers, running meetings

(g) The financial side of being involved in a SRP

(h) How effective you thought the SRP was/would be

(i) Whether you thought it would be detrimental in any way

(j) The opinions of other people you know about the SRP

(k) The space needed to set up a Son-Rise playroom

(l) The fact that running a SRP sometimes lasts a number of years.

(m) Thoughts about using other therapies/approaches

(n) The isolation (in that you may have been on your own in the house for a lot of the time)

(2) Did any other factors contribute to your decision?

**(2) Support from the Option Institute**

(a) Looking back, do you feel that the Start-Up course prepared you well for running a SRP, or do you feel it prepared you well in some ways but not others?

**(3) Other therapies**

(a) Are you considering other therapies or are you happy with the way things are going?

*Prompt* - (if yes) what attracts you to that therapy?

**(4) Overall**

(a) How do you feel now about your decision not to undertake a SRP?

(b) How would you sum up your experiences of the SRP?

(c) Do you continue to use the techniques or do you feel they are not suited to your child?

*Prompt* - (if yes) in what way?

*Prompt* - (if no) why is that?

(d) Do you continue to use the SRP attitude or do you feel that it is not suited to your child?

*Prompt* - (if yes) in what way?

*Prompt* - (if no) why is that?

### **Interview 3 schedule**

#### **(1) Your child and your Program**

(a) How is your Program going just now?

(b) Roughly how many hours is the Program running for each week?

*Prompt* - how do you feel about that, are you happy with the number, or would you like to do a different number of hours?

*Prompt* - What prevents you doing more/fewer hours each week?

(c) How is your child reacting to the SRP and the playroom just now?

*Prompt* - how is s/he reacting to the techniques?

- how is s/he reacting to being in the room?

(d) Can you give me examples of the sorts of progress, if any, that you feel your child has made since the last interview?

*Prompt* - you could consider areas such as language, social interaction, toilet training, eye contact, attention, and academic skills.

(e) Which of these improvements would you attribute to the SRP and which to other things?

(f) Could you tell me about any areas of your child's development where progress has been less than you would have hoped for since the last interview?

*Prompt* - you could consider areas such as language, social interaction, toilet training, eye contact, attention, and academic skills.

*Prompt* - why do you think that is?

(g) Has your child's **rate** of progress varied since the time you began your SRP, or has it stayed the same?

*Prompt* - for example was your child's progress initially slow and then it speeded up, or maybe the other way round?

*Prompt* - (if it has changed) why do you think that is?

(h) Have you made any decisions about when your Program will end?

*Prompt* - why have you decided to end it then?

#### **(2) You**

(a) How are you currently finding working in the room with your child?

*Prompt* - are there aspects you particularly like or dislike, or that you feel particularly confident or not confident about? Why is that?

(b) How confident do you feel just now that you are going in the right direction with your child. What I mean by that is how confident do you feel about knowing what to do next, knowing whether you are challenging your child too much/too little etc.?

(c) Do you think your way of working in the room has changed at all since you began your SRP, or has it stayed much the same?

*Prompt* - (if it has changed) in what way has it changed?

(d) Do you get feedback from anyone on the use of your techniques?

*Prompt* - (if no) How do you feel about that?

*Prompt* - (if yes) who gives you your feedback?

- (if yes) what is your experience of receiving feedback? Do you enjoy receiving it, or not, do you find it easy to implement suggestions or not?

(e) How is your working life currently fitting in with your SRP?

(f) Has using the SRP changed you at all or not really?

*Prompt* - (if yes) in what way?

#### **(3) Family**

(a) Could you tell me a little bit about what the effects have been, if any, of the SRP on your family over the past 6 months?

*Prompt* - how about on your husband? Does he work in the room with your child?

*Prompt* - how about on your other children?

*Prompt* - how do you feel about that?

(b) Has family life changed or stayed the same in terms of stress since you began your SRP?

(c) Has family life changed or stayed the same in terms of happiness since you began?

**(4) School**

(a) How do you feel now about the decision you made about your child's schooling (i.e. whether to continue, discontinue etc)?

(b) How is the SRP currently fitting in with your child's schooling?

*Prompt* - are they taking an interest? If so, in what way?

(c) Do you think there are any differences between the way people interact with your child in the room and how people interact with him at school?

*Prompt* - (if yes) - what are the differences?

*Prompt* - (if yes) how do you think your child copes with those differences?

**(5) Volunteers**

(a) Do you currently have volunteers? How's that working out?

*Prompt* - how about recruiting/giving feedback/ having meetings?

- how about the number of hours they work for each week?

*Prompt* (if no volunteers) - what are the reasons for you having no volunteers, for example is it because of where you live, or is it a bad response to publicity?

**(6) Therapies**

(a) Are you considering other therapies just now or are you happy with the way things are?

*Prompt* - (if yes) what attracts you to that therapy?

*Prompt* - (if it's an interactive therapy) How do you think that will fit in with your SRP?

**(7) Support**

(a) Have you used the follow-up support available since the last interview, and if so what has been your experience of it?

(b) Did you attend the Maximum Impact?

*Prompt* - (if yes) what was your experience of it?

*Prompt* - (if no) what were the reasons for you not attending?

(c) What are your thoughts now about the Intensive Program in America?

*Prompt* - are you still planning to attend it?

(d) Are you in touch with other families who are using the SRP?

*Prompt* - (if yes) do you find it helpful being in touch with other families or not really?

*Prompt* - (if no) would you like to be?

**(8) Fund-raising**

(a) Is there any fund-raising going on just now for your SRP?

(b) How are you currently finding the financial side of running your SRP?

**(9) Overall**

(a) How do you feel now about your decision to undertake a SRP?

(b) How would you sum up your experiences of the SRP so far?

(c) What, if anything, do you think would make the SRP easier to implement, for you in particular, and for families in the UK in general?

(d) Is there anything that you would like to add that you feel I haven't covered?

### **Interview 3 schedule (for family no longer running SRP)**

#### **(1) Your child**

(a) Can you give me examples of the sorts of progress, if any, that you feel your child has made since the last interview?

*Prompt* - you could consider areas such as language, social interaction, toilet training, eye contact, attention, and academic skills.

(b) What would you attribute these improvements to, for example, school, interaction at home, growing older?

(c) Could you tell me about any areas of your child's development where progress has been less than you would have hoped for since the last interview?

*Prompt* - you could consider areas such as language, social interaction, toilet training, eye contact, attention, and academic skills.

*Prompt* - why do you think that is?

(d) Has your child's **rate** of progress varied in the past year, or has it stayed the same?

*Prompt* - for example was your child's progress initially slow and then it speeded up, or maybe the other way round?

*Prompt* - (if it has changed) why do you think that is?

#### **(2) You**

(a) Has using the SRP changed you at all or not really?

*Prompt* - (if yes) in what way?

(b) Did your interactions with your child change after the SRP, stay much the same?

(c) Do you continue to use any of the techniques or do you feel that they are not suited to you or your child?

*Prompt* - (if yes) in what way?

*Prompt* - (if yes) can you give me an example?

*Prompt* - (if no) why is that?

(d) Do you continue to use any of the attitudinal side or do you feel that it is not suited to you or your child?

*Prompt* - (if yes) in what way?

*Prompt* - (if yes) can you give me an example?

*Prompt* - (if no) why is that?

#### **(3) Family**

(a) Could you tell me a little bit about what the effects have been, if any, of your child and his autism on your family?

*Prompt* - how about on your husband?

*Prompt* - how about on your other children?

*Prompt* - how do you feel about that?

(b) Has family life changed or stayed the same in terms of stress since your child was diagnosed?

(c) Has family life changed or stayed the same in terms of happiness your child was diagnosed?

#### **(4) School**

(a) How is your child getting on at school?

#### **(5) Therapies**

(a) Are you considering any other therapies just now or are you quite happy with the way things are?

*Prompt* - (if yes) what attracts you to that therapy?

*Prompt* - (if it's an interactive therapy) How do you think that will fit in with your SRP?

#### **(6) Overall**

(a) How do you feel now about your decision not to undertake a SRP?

## APPENDIX E

### VIDEO CODING SYSTEM (STUDY 4)

#### **Mother's behaviour - imitation**

The adult copies what the child is doing verbally or physically. If the child is using a toy/object the adult either uses another object or pretends to have one.

Can be an imitation of:

- verbalisation (including any noises, even if they are not words)
- action (including positioning if this is unusual)

The following verbalisations should not be classed as imitation:

- When the child has requested something or answered a question and the mother repeats back what the child has said, and the function seems to be agreement rather than imitation. E.g. the mother says "what do you want?" and the child says "ball", and the mother repeats "ball". The exception to this is if the mother is treating the child's request as echolalia and is clearly imitating the tone etc. of the child's utterance.
- If the child says something which is incoherent and the mother repeats it in a questioning tone, as if to establish what the child meant.
- If the child says something incoherent and the mother repeats but much more coherently.
- Other repetitions where the mother's tone seems to make her statement serve a purpose other than imitation, e.g. repeating what the child has said but in a disbelieving/surprised/confused tone. Note that the mother can imitate in a different tone of voice/ at a different volume, as long as the sole purpose seems to be imitation, e.g. she may whisper back what the child has said to give some variation.
- Singing songs/performing action songs together is not classed as imitation.

The following should be classed as imitation:

- If the mother imitates exactly but asks a question about the child's verbalisation afterwards. E.g. the child says "beepbeepbeep" and the mother says "beepbeepbeep.... what does that mean?"
- If the child is in an unusual position (e.g. curled up in a ball, or lying on floor with feet up on the wall) and the mother imitates the child's positioning. Positioning should only be classed as imitation if it is an unusual position – e.g. if the mother and child were both sitting in a regular position on the trampoline this would not be classed as imitation.

Note there are lots of sequences of the child jumping on the trampoline. The mother is only classed as imitating if she is also jumping and/or imitating the arm/facial movements of the child. It is classed as imitation even if the mother is jumping on the floor rather than the trampoline. The mother is not classed as imitating if she is simply supporting the child's hands while the child jumps.



There is a difference between working on the same task and imitation, e.g. mother and child could both be drawing, but it wouldn't be imitation unless the mother was obviously copying the actions made by the child, e.g. reaching to get a new colour of pen at the same time, sitting in the same posture etc.

### **Mother's behaviour – praise**

The adult commends the child's activity/verbalisation either explicitly (e.g. "oh, that's a lovely song you're singing") or implicitly (e.g. "yeah, you're singing a song!" - said in an cheering way). This commentary can also be related to eye contact, and again be explicit (e.g. "oh, what a beautiful look") or implicit (e.g. "oh, you're looking at me" - said in an approving tone). The praise does not have to be verbal, e.g. the adult could clap or cheer, but it must be clear that it is directed towards what the child has just said or done.

Praise can be for the following:

- Mother praises child's own activity, rather than for something that the mother asked the child to do.
- Mother praises the child for succeeding or attempting to comply with a request.
- Mother praises for refusal/no attempt - the child refuses to do what the mother has requested or does not attempt, and the mother praises the child for this.
- Praise must be clearly directed towards something the child has just done. Cheering during a joint activity does not count as praise unless it is clearly directed to an action on the part of the child.
- Thanking the child counts as praise, e.g. "thank you for that look", "thank you for telling me that."
- Repeating back the what the child say and adding "wow" or "that's interesting" at the end of the sentence does not count as praise – this is simply showing interest in what the child has said, it is not praising them for saying it.
- If there are several sentences of praise together it just counts as one instance, but if there is a gap between them (e.g. during which the child speaks) it is counted as two instances of praise, even if the praise is for the same thing.
- If the child answers and the mother simply says 'yes' or "that's right", it is not classified count as praise, but if she says it in a tone which seems to be really cheering the child "yeeaahh!" then it is praise.
- If the mother says 'what a good idea!', this counts as praise – and is generally either related to an action the child has just performed, or their verbalisation about an idea.

### **Mother's behaviour – requests**

The mother asks the child to do something - to answer a question, make a choice or comply with an instruction/suggestion. The mother can also request indirectly for the child to do something.

For any request it must be clear (a) that the mother wants the child to do something (b) what the mother wants the child to do.

### Types of request:

- Choice. The adult gives the child the option of choosing from two activities/objects (“Do you want the red car or the green one?”)
- Question/suggestion The adult asks the child something which requires either an answer from the child, or that the child does something (e.g. “Why don’t you push that train over to me?”). This can be related to eye contact (“why don’t you look in my eyes?”). Questions/suggestions can be for something that the mother wants the child to do alone or a suggestion of something they can both do together (‘why don’t we go and jump on the trampoline’). Excluded are questions which offer a choice.
- Instruction. This is more didactic. Rather than suggesting, the adult *tells* the child to do something (“Push that train over to me.”). The instruction can be related to eye contact (“Look in my eyes.”)
- Indirect request. The adult makes it clear that they require the child to do something specific, but does not use words, or uses words that do not form an explicit request. Rather than the words, it is the mother’s gesture, expectant look, pause, or withholding of some action that indicate that the mother is requesting something. It must be clear (a) that the mother requires the child to do something (b) what the mother requires the child to do. Examples include:
  - The mother pointing in her eyes and looking expectantly at the child to indicate that she wants the child to make eye contact.
  - The mother singing a song and then pausing before a word to indicate that she wants the child to fill in the next word.
  - The mother beginning to count a collection of objects and then pausing after counting a few and looking at the child to indicate that she wishes him to continue the counting.
  - In the context of a game where the child has previously been asked to say a word in order to get a reward (e.g. a tickle) the mother being poised showing she is ready to deliver the reward and looking expectantly at the child.
  - The mother saying “ready” and clearly waiting for the child to say “steady, go.”
  - In the context of a turn taking situation where the mother and the child have already both taken a turn, the mother has had another turn and then looks expectantly at the child indicating that it is the child’s turn again.
  - Simply the mother saying what she is doing is not enough. For example if the mother says “I’m hiding” this is not clearly a request for the child to go and find her (although this maybe what she wants the child to do). Another example is the mother saying “I’m coming to get you!” is not clearly a request for the child to run away.

### Notes on requesting:

- Questions must be clearly directed towards the child to be included. Note that the mother may make questions which, rather than being directed towards the child, are a commentary on what the mother is doing. For example if she is looking for a car on the shelf and says “Oh, where’s that car gone? Oh, there it is.” And the question is not directed towards the child it would not be classified under requests.
- After making a request the mother may give help or encouragement to the child to assist them in complying with the request. For example she may repeat the phrase that she wishes the child to say, and offer encouragement e.g. ‘come on, I know you can do it!’ This is a prompt rather than a repetition of the request.
- The word “ready” is not coded as a request unless it is very clearly a question (e.g. short for “are you ready?”) or a silent request (for the child to say “steady, go” afterwards).

### **Do not include as requests**

Be careful – although some phrases have the grammatical structure of a question, suggestion or instruction they should not be coded as requests:

- Phrases which, although they have the grammatical structure of an instruction are in fact admiration rather than instruction e.g. “Oh wow! Look at that painting you’ve made!”
- Questions where the mother does not appear to expect an answer but instead is making a commentary on what the child is already doing. E.g. if the child is bouncing on the trampoline the mother saying “oh, you’re bouncing are you?”
- Other questions where the mother does not seem to expect an answer but is just keeping the interaction going e.g. “what are you up to?” when the child is running away.
- Questions where the mother is just repeating back what the child has said to express interest e.g. if the child says “I’m going on the bus” and the mother says, “oh, you’re going on the bus are you?”
- If the mother answers the question/performs the behaviour she has asked the child to do herself before the child has time to answer.

### **Notes on multiple requests**

- Multiple requests should be noted. This is where the mother repeats the same request before the child has complied with the original statement.
- It will still be classed as a multiple request if the words used each time are different, as long as their purpose is the same, to get the child to do the same thing.
- Note that in ‘multiple requests’ one of the conditions is that the child doesn’t successfully complete the request during the multiple requests. E.g. a game where the child succeeds and then the mother gives the same request again for the child to repeat the action would not be classified as multiple requests, rather it would be a series of original requests.
- If the child does comply with the request, but the mother does not seem to be aware of this and continues to repeat the request, continue to code as multiple request

### **Mother’s behaviour - non Son-Rise behaviour**

Adult uses behaviour which is at odds with the Son-Rise philosophy of acceptance and respect for the child’s choices. Will be of the following type:

- **Disapproving comment/criticism**
  - Excludes offering suggestions for alternative behaviour, e.g. “instead of screaming you could just say no.”
  - Must be genuinely disapproving as opposed to being part of some game.
  - Excludes anything relating to the camera or me.
  - Excludes when the mother tells the child not to do something which is a safety issue, e.g. telling the child not to climb up on something high, or telling them not to hit the mother – as long as this message is conveyed in a Son-Rise way, e.g. without anger or telling the child they are bad.

- **Physical manipulation**
  - The adult physically moves the child against the child's will. In this case the child should be clearly objecting to the adult's actions, either verbally or non-verbally.
  - Excludes the mother lifting/pulling the child away from the camera.
  - Includes physical manipulation to stop the child leaving the room.
  - Excludes instances where the mother stops the physical contact, as soon as the child makes it clear that they are objecting to it.
- **Requesting despite child's refusal**
  - The adult continues to challenge a child with a question, instruction, choice or silent request, despite the child making it clear, either verbally or non-verbally, that they don't wish this to happen.
  - Do not code for this just because the adult is being persistent with a request, its only if the adult persists after the child has refused to comply that it should be coded.
- **Selecting task when child occupied**
  - The mother selects a new activity when the child is occupied in something else.
  - Excludes anything the mother does to get the child away from the camera.
  - Only include tasks that would require the child to stop the task that they were currently doing in order to start the mother's task.
  - Excludes tasks the mother selects to give the child an alternative to leaving the room or trying to get the door key, e.g. "we'll be leaving in a little while, lets do a jigsaw till then."
  - If same task introduced twice in a row while the child is occupied only code once as non Son-Rise, but if tries different tasks put as non Son-Rise each time. If the same thing is introduced twice with other tasks introduced in between all would count as non Son-Rise.
- **Denies child's request**
  - Requests can be verbal or non-verbal.
  - Excludes requests to leave the room/get the key for the door.
  - Excludes requests which are impossible for the mother to fulfil, e.g. requests for a toy which is not in the room.
  - Note denying, as opposed to not noticing or not understanding.
  - There must be actual refusal on the part of the adult to give the child what they have requested, as opposed to holding out for language before giving the child what they want.

### **Mother's & child's behaviour – laughing**

- Laughing and giggling are included in this category.
- Laughing must be audible, i.e. you cannot code for laughter if you can't hear the laughter even though the child is shaking as if they are laughing.
- If one of the pair laughs and then stops for a second or more and then starts laughing again, this should be coded as two instances of laughter. If the pause is for less than a second it can be coded as one continuous piece of laughter.

## **Mother & child behaviour - task selection**

Task selection can be made either by the mother or the child. It is when one begins doing something which wasn't being done immediately beforehand.

Notes on task selection:

- If a task is suggested but not actually carried out it would still be classified as new task selection. For example if the mother said "lets play with the ball", and the child did not play with the ball, it would still be classed as the mother making a task selection.
- If the child does not say they are beginning a task but just starts doing something they must do it for more than 10 seconds before it is classified as a task.
- Selection of a new task is more than simply expanding the previous task (i.e. using aspects of the ongoing task and extending it) - they are going in an entirely new direction.
- The child could use the same toys/objects as were being used in a previous task, but would have to use them in a totally different way for it to count as a new task rather than an extension of the previous task.
- The child could swap toys but not have changed task, e.g. if playing cars and moves from a car to a bus.
- The child does not have to use toys/objects in the task.
- Not every small change in the child's ongoing activity would count as a new task. For example the child dipping brush in paint, painting on paper and washing brush in water would all come under the one task of 'painting'.
- If the child only does a stereotypical movement briefly during an ongoing task (less than 10 seconds) then the task doesn't count as a new task. However, if there is no other task going on and the task seems to be the main focus of the child's attention, then it would count as a new task.
- Child can change location in the room and still be doing the same task.
- Conversations do not count as a task if they are going on at the same time as something else which seems to be the main focus of attention. They do count as a new task if it is the conversation which has become the main focus.
- Tasks sometimes overlap, making it difficult to code where one begins and the other ends. The key is to look at what the main focus of attention is.
- If mother repeats selection of task it should not be coded twice (e.g. if mother suggests singing and child does not respond and mother repeats selection then it only counts as one task selection). However, if they move onto another task and the mother then repeats an earlier suggestion then it would be coded as a second task selection.
- If the mother suggests either blowing the child's nose or the child going to the toilet these are not coded as mother task selection because they are reacting to something the child is doing and thus extending the child's activity rather than suggesting a completely unrelated task. For example in many cases the child is squirming about and the mother thus suggests going to the toilet.
- If the mother selects a task and the child doesn't do it and continues with their own task it is coded as 'kidtask, mumtask' rather than 'kidtask, mumtask, kidtask'.
- Sometimes the child extends their own activity, rather than beginning a new activity. If the mother then extends this again the pair may then be doing something fairly different from what they were doing originally, but they have not begun a new task.
- Sometimes it is impossible to tell who has selected the task, e.g. when the camera has been switched off because the child had left the room, was using the potty, or there had been some

disturbance, and then a new task had been selected before the camera had been switched on. In these cases it is coded as 'task – don't know'.

- Often the mother suggests a task because of what the child is looking at, e.g. the child gazes at the ball and the mother suggests playing with the ball. In this case it would count as a kidtask selection.
- Songs count as a new activity if they are suddenly begun, but not if it is an extension of the context (e.g. tickling toes leading to 'This Little Piggy'.)
- If child moves away but is not clearly involved in a new task and mum redirects back to the previous task then it is not categorised as 'mum task'.
- If child moves away and becomes involved in a new task and then mum redirects back to previous task then this is coded as 'mum task'.
- If child moves away, becomes involved in new task, stops the new task, then mum redirects back to previous task then this is categorised as 'mum task'.
- There should be consistency in coding between the mother and child – for example if something counts as a new task if the child does something then it would also count as a new task if the mother did it.

### **Tasks relating to the camera**

- If the child approaches the camera this is not classified as a new task.
- If the mother directs the child from the camera but selecting a task it is not categorised as a new task.
- If the child approaches the camera and then goes on to a new task that they were not doing previously this would count as a new task.

### **Child's behaviour - spontaneous physical contact**

Where the child touches the mother. It can be either (i)neutral/positive or (ii)negative. Neutral/positive includes hugging, holding hands, leaning against, holding the mother for support. Negative is when the contact is aggressive, and takes the form of biting, scratching, hitting.

Notes for physical contact:

- This only includes physical contact that the child has initiated, not contact that the mother has initiated.
- It does not include physical contact that the mother has asked the child to make, e.g. if she has asked the child to hold her hand or sit on her knee.
- However, if the child then made physical contact over and above what the mother had initiated or asked the child to make then it would be included. For example, if the mother has asked the child to sit on her knee, and the child then puts her arms around the mother's neck, this arm movement would be classed as physical contact.
- If the child is pulling or pushing the mother this would be classed as neutral/positive rather than negative, unless it seemed to be aggressive.
- If the child is touching an object the mother has, or is touching the mother with an object, this is not included as physical contact.
- Note that in some cases the physical contact will be prolonged because the mother has made a response to the child's initiation of physical contact, e.g. the child has come to sit on the mother's knee and the mother gives the child a cuddle. As with other instances of physical contact the contact ends when one person breaks away from the other.

Coding the end of physical contact:

- Physical contact ends once there is no body contact at all between the mother and child.
- If there is the smallest bit of physical contact, e.g. the child having a toe in contact with the mother's leg then this is still coded as physical contact until there is no contact at all.
- If the mother has initiated the physical contact, but the child has made physical contact above and beyond this (e.g. she is cuddling him, but he puts an arm around her), the physical contact is coded as being ended once the piece of contact that the child initiated (e.g. the arm around the mother) has ended.
- Physical contact can move from being positive to negative with no end of physical contact in between.

### **Child's behaviour - vocalisations**

The child makes a vocalisation. It will not necessarily be a complete word – it could be a word approximation.

Within this speech will be one of three types:

- Proper words – it is possible to make out what the child is saying, although their words will not necessarily be grammatically correct, or be the correct answer to something the mother has asked.
- Echolalia – Either immediate echolalia, where the adult says something and the child immediately says it back in a similar tone, or delayed echolalia.
- Word approximation – this includes babbling, saying part of a word. Anything where the child's noises have a speech-like quality, but it is not possible to distinguish what they are saying. Can be short, e.g. just a syllable or a letter.

Additional notes on speech:

- If the child is whispering and it is therefore impossible to tell if they are using proper words or echolalia, do not include it in the analysis.
- Do not code squeals of delight, crying or whining as vocalisations.
- Do not code animal noises, car noises or plane noises as vocalisations, as these will never develop into words.
- Coding is based on what you can hear, not what the mother can hear. If you think the child has made a word approximation code it as this, even if the mother thinks the child has said a whole proper word.
- Similarly do not code as a vocalisation just because the mother praises the child for making a vocalisation, unless you could also hear it clearly enough to categorise it.

Recognising delayed echolalia:

- Often refers to TV characters, fictional stories, when there is nothing about them present, e.g. saying lines from Postman Pat when there is no Postman Pat book to look at.
- Often seems out of context.
- May consist of the child repeating phrases which have obviously been said to him/her previously.
- May be repeated over and over.

## **Child's behaviour – eye to face contact**

This is when the child looks at the mother's face. Code only when certain that the child is looking at the mother's face, not if there is a possibility that their gaze could be directed elsewhere.

Notes for eye to face contact:

- Do not code unless both mother and child are visible on the screen.
- Do not code unless you can see the child's eyes – even if they have their face turned to the mother's face they could be gazing at the floor.
- Do not code if you can only see the back of the child's head – even if their head is turned in the direction of the mother's face.
- You do not need to be able to see the whites of the child's eyes, as long as you can tell that the direction of gaze is at the mother's face.
- If camera is out of focus and you cannot see the child's eye's clearly do not code, unless it momentarily goes out of focus in the middle of eye contact, and it was clear that eye contact occurred before and after.
- Do not code just because the mother is praising eye contact – she may be able to observe eye contact that you cannot (e.g. she may be able to see the child's face when you can only see the back of their head).
- If the mother is holding something close to their face that isn't concealing her face and the child is looking at it than code as eye to face contact, because the child will be able to see the mother's face at the same time.
- The child does not need to be looking in the mother's eyes, it can be anywhere on the mother's face (but not top of head, must be face).
- You can code if you can only see the side of the child's face (i.e. one eye or side of one eye) as opposed to seeing them face on, if you are sure that eye contact has occurred.
- Be wary about coding when the child is bouncing on the trampoline or when the child is lying down, as it is more difficult (although not impossible) to be certain that eye contact has occurred in these situations.

## **Child's behaviour – stereotypical movement**

- Any simple repetitive movement made by the child including hand flapping, flicking fingers in front of face, spinning objects in hand.
- The child is normally (not always) non-interactive during this behaviour, being totally absorbed in the stereotypical movement.
- If child stops for more than a second and then starts again this should be coded as two instances of stereotypical behaviour. If the pause is for less than a second it should be coded as one continuous piece of stereotypical behaviour.



## APPENDIX F

### GRAPHS ILLUSTRATING CHILD'S BEHAVIOUR AND MOTHER'S USE OF SRP TECHNIQUES (STUDY 4)

Three graphs were plotted for each mother-child pair. For each pair all graphs display the changes in the mother's use of imitation and requesting over time, with the first also displaying changes in the child's physical behaviour over time (spontaneous physical contact and stereotypical behaviour), the second the child's laughter and spontaneous eye to face contact, and the third the child's spontaneous vocalisations (word approximations, proper words and echolalia).

In all graphs the child's behaviour and the mother's use of imitation are expressed as the percentage of the 20-minute session during which the behaviour was displayed. These relate to the 1<sup>st</sup> y-axis and are displayed as solid lines. The mother's requests are shown in terms of absolute number per session. This behaviour relates to the 2<sup>nd</sup> y-axis and is displayed as a (single) broken line on each graph. The range of both the primary and the secondary y-axes varies across graphs in order to represent as clearly as possible the relation between the patterns of change in the child's behaviour and the mother's techniques. While the pattern of change is more relevant than the absolute percentage/number of occurrences, care should nonetheless be taken in interpretation of these graphs.

Not all children displayed all types of behaviour. Therefore in the graphs for pairs H and J no echolalia is shown, and the graphs for pairs J and L show no stereotypical behaviour. In addition negative physical contact was at such a low level for all the children throughout the study that it is not shown in the graphs for any pair. In all cases the physical contact shown on the graph refers to positive/neutral physical contact. The only case where there was a significant level of negative physical contact was in pair K, session 5. Here Kevin displayed negative physical contact for around 9% of the session (not shown on the graph). This was caused by a combination of factors outside the playroom which led to a very atypical and unsettled session.

## Pair G

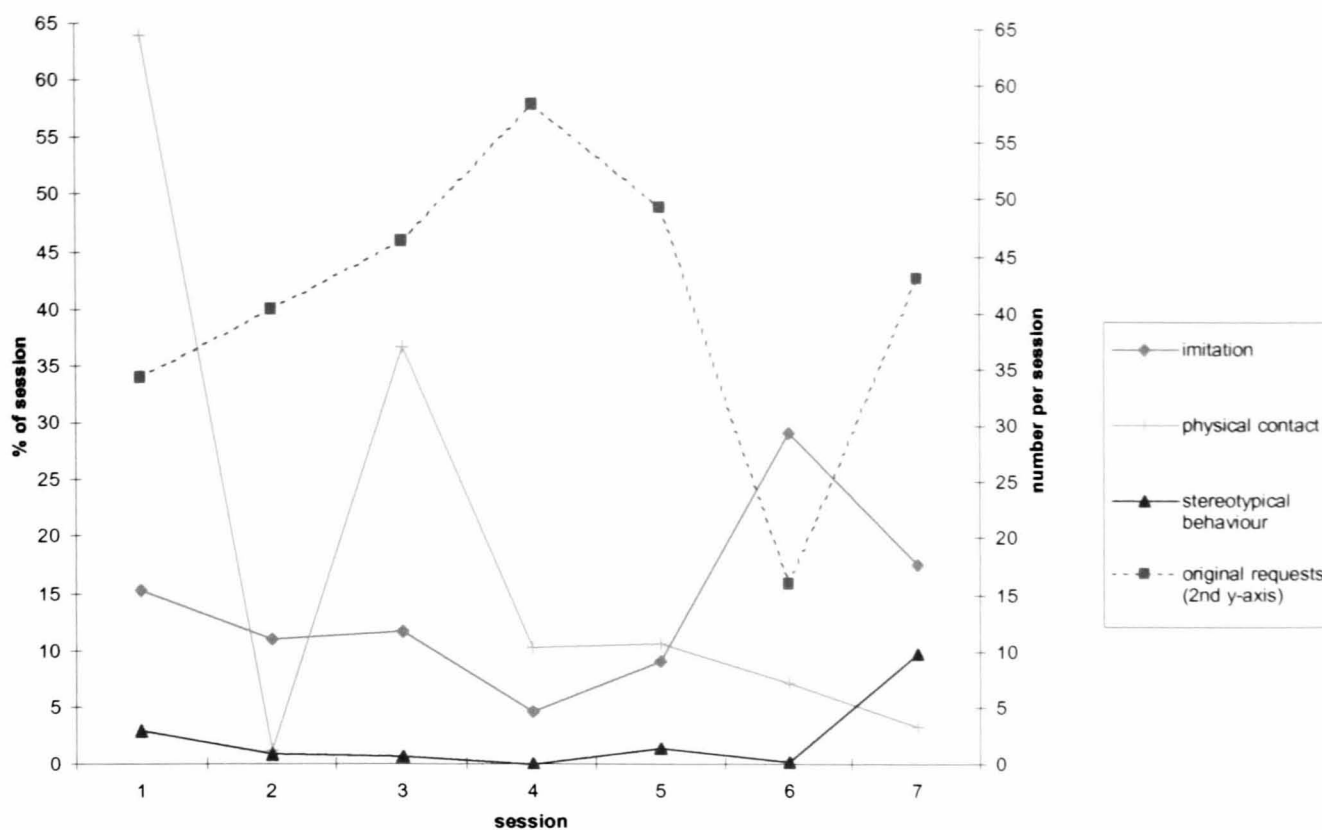


Figure F1: Pair G – relation between child's physical behaviour and mother's techniques

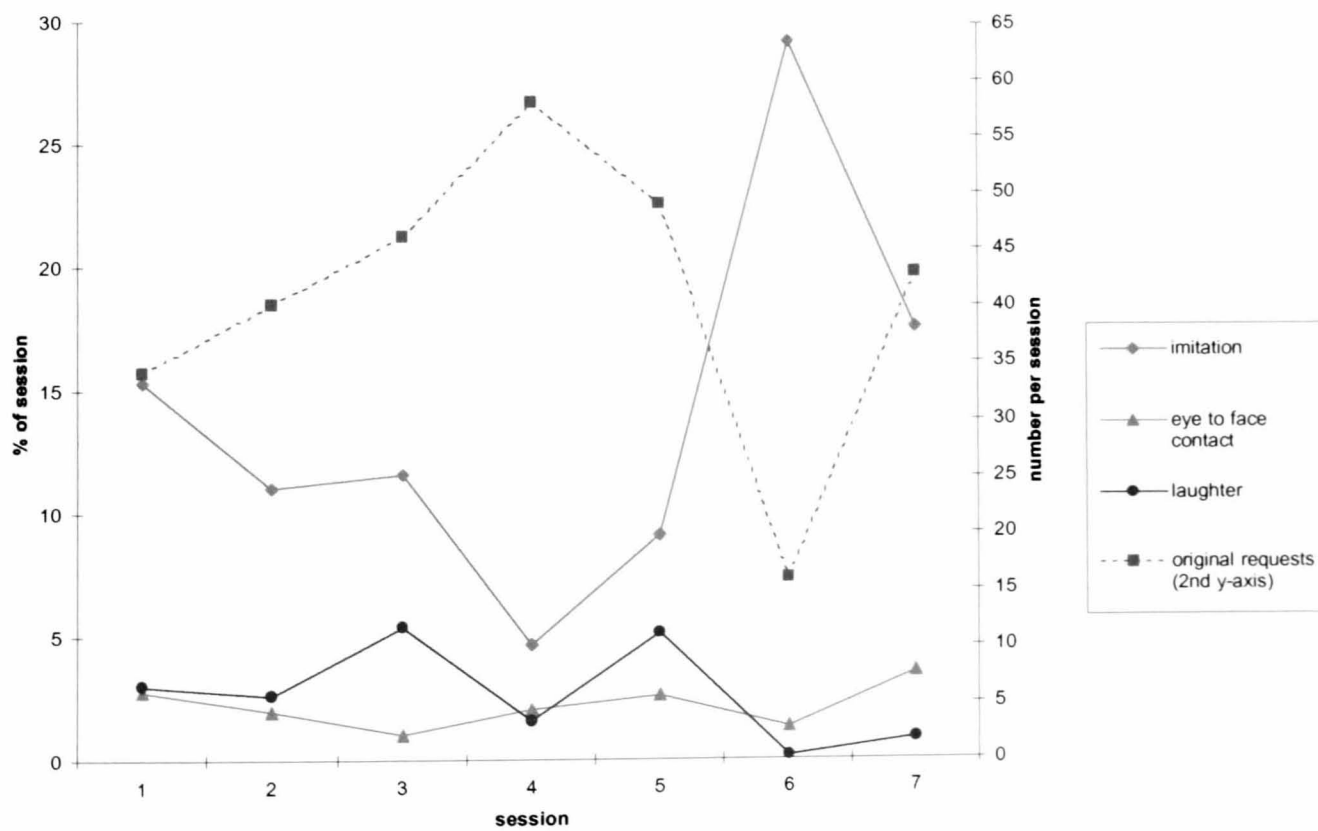


Figure F2: Pair G – relation between child's behaviour and mother's techniques

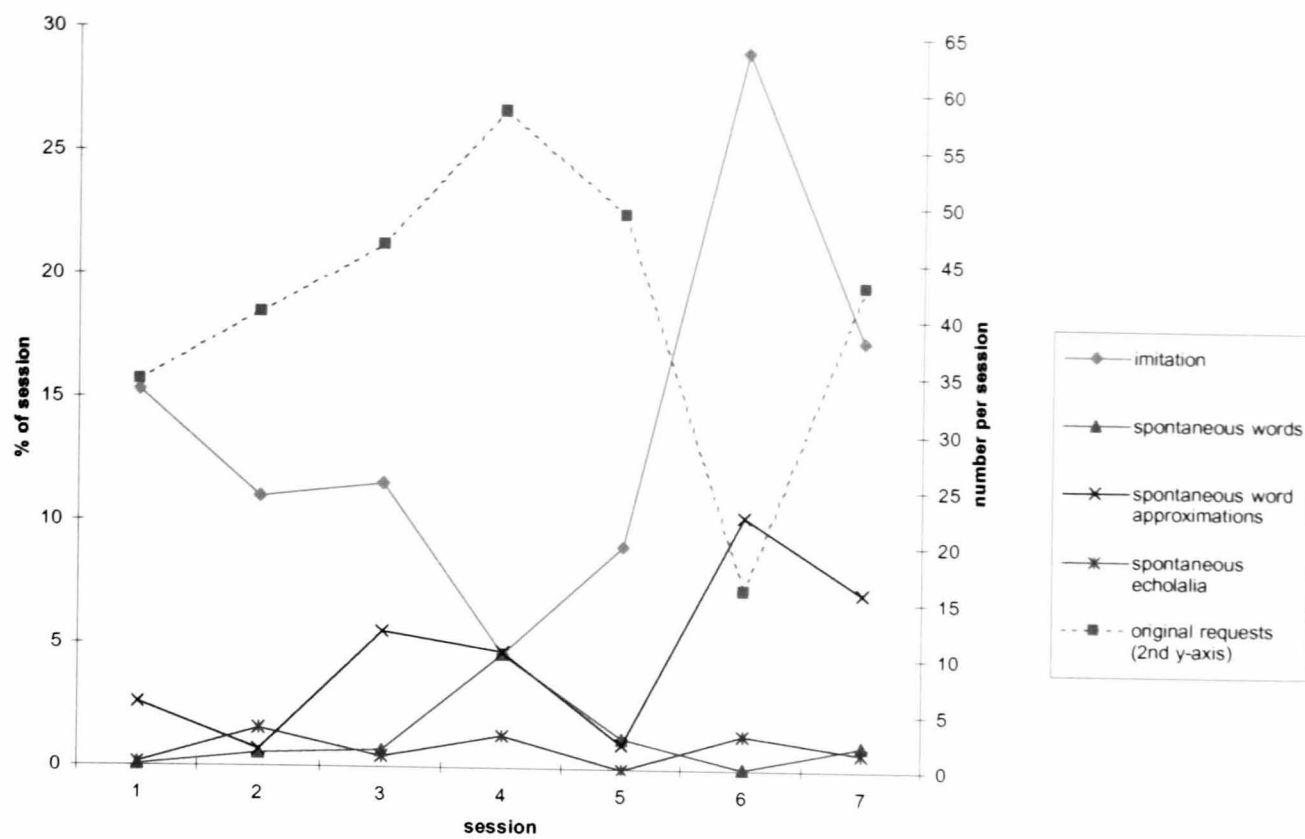


Figure F3: Pair G – relation between child's vocalisations and mother's techniques

## Pair H

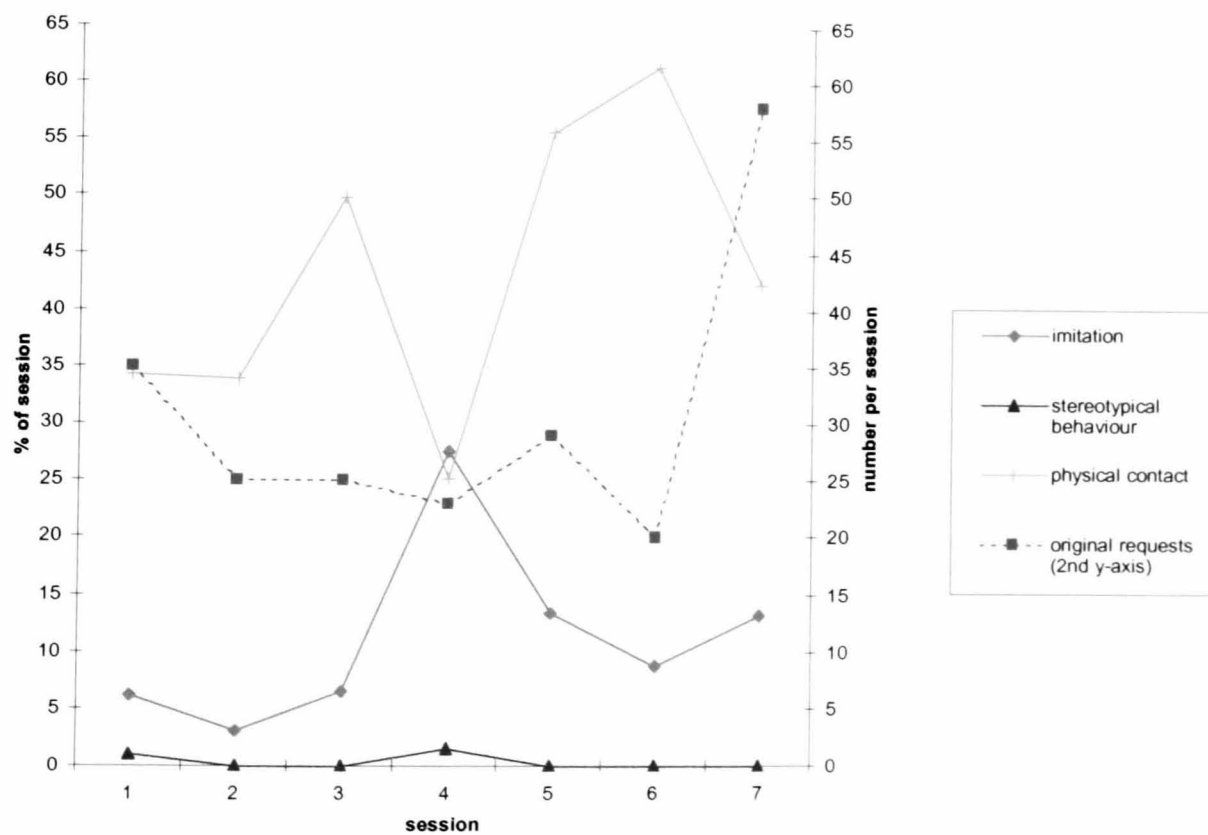


Figure F4: Pair H – relation between child's physical behaviour and mother's techniques

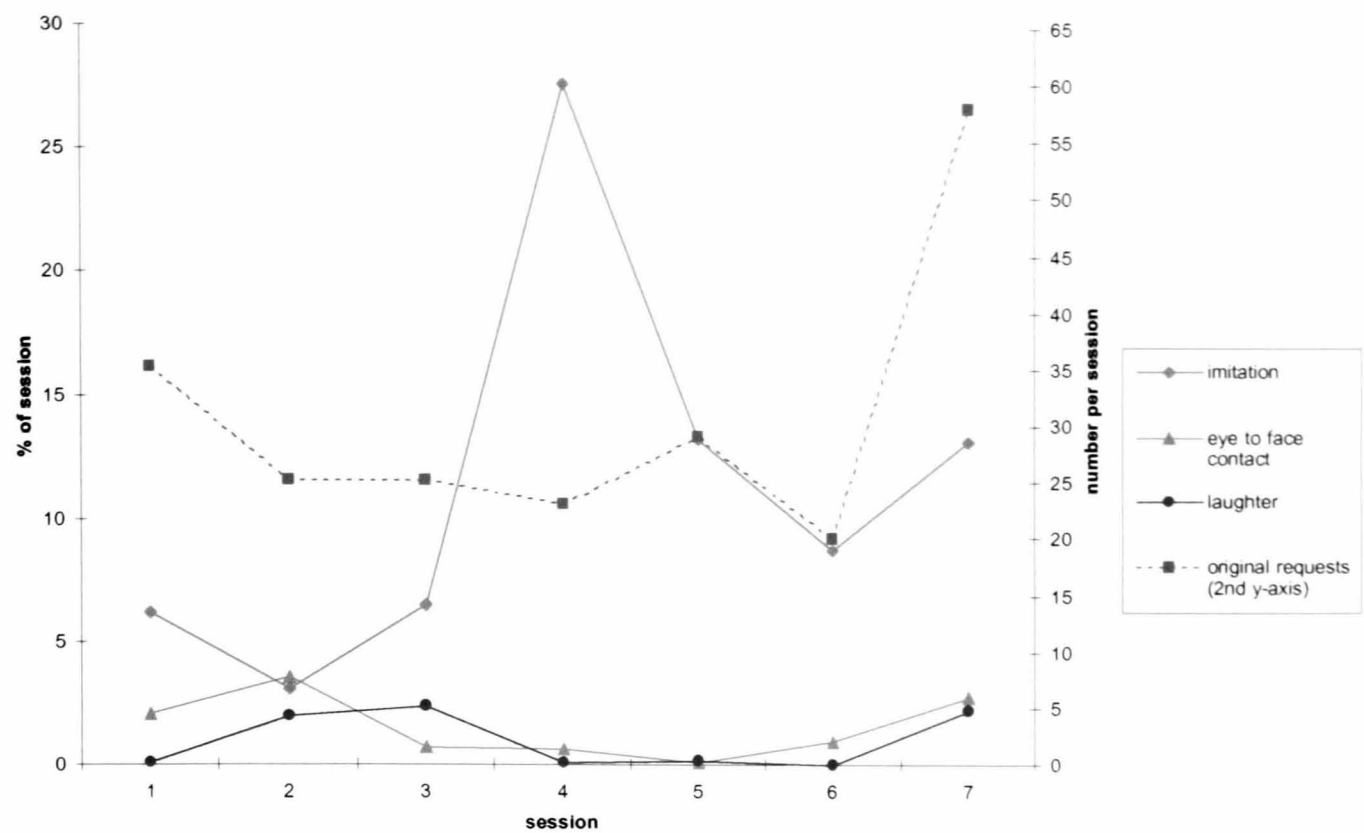


Figure F5: Pair H – relation between child's behaviour and mother's techniques

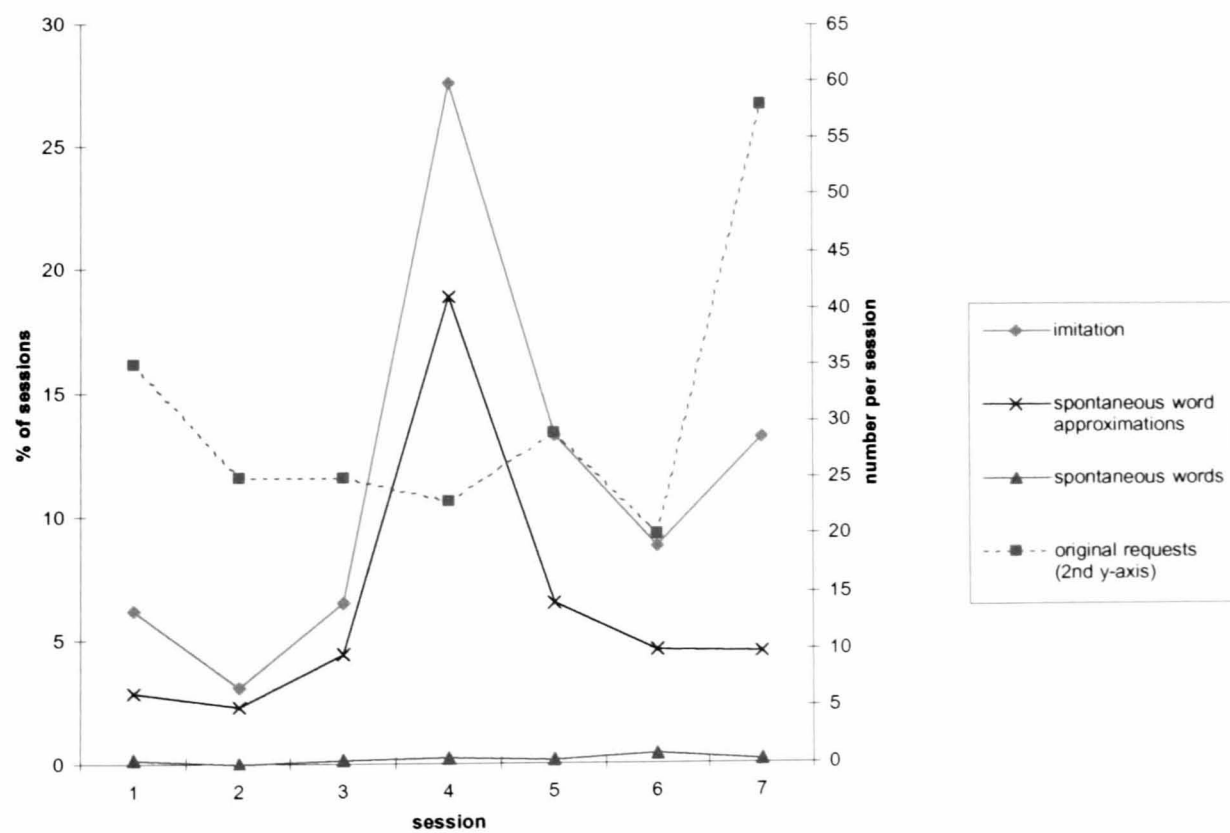


Figure F6: Pair H – relation between child's vocalisations and mother's techniques

Pair I

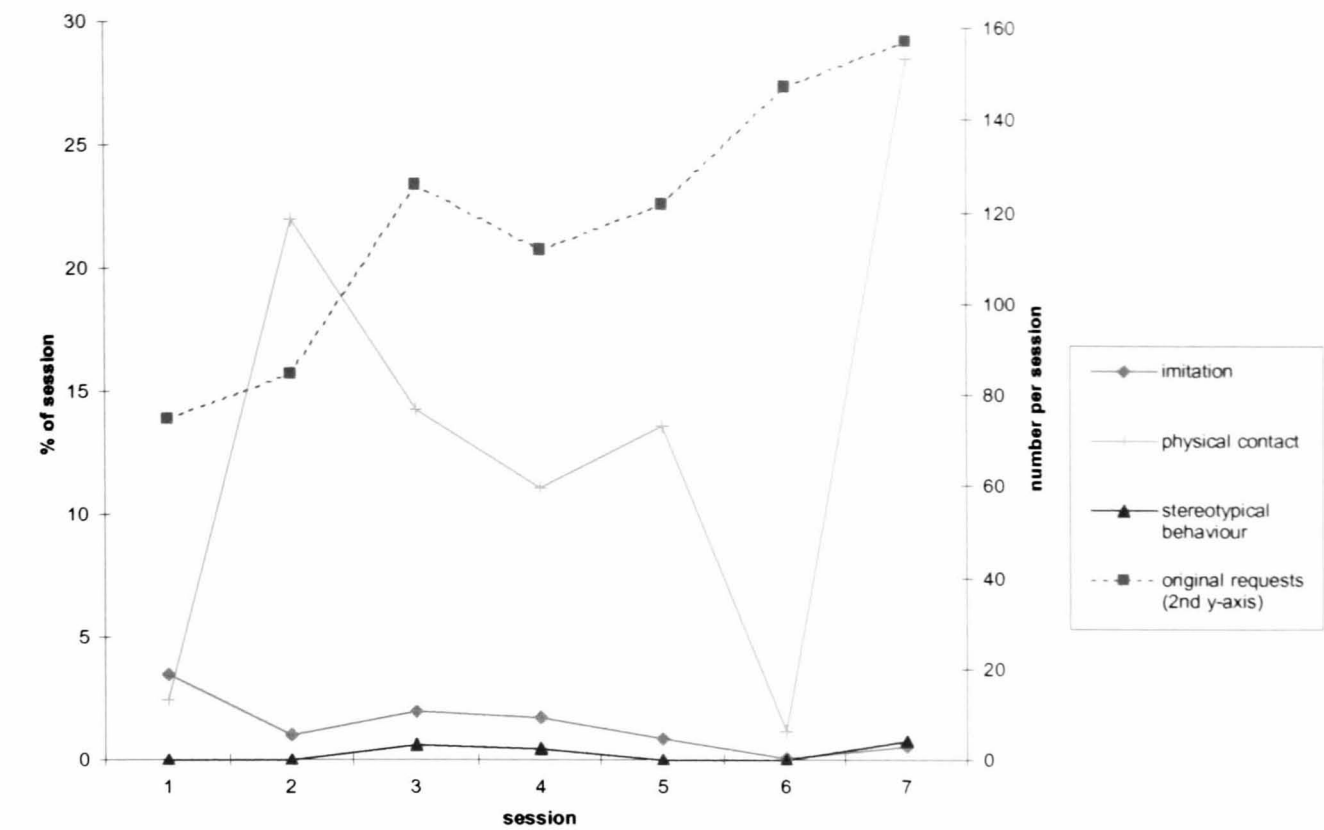


Figure F7: Pair I – relation between child’s physical behaviour and mother’s techniques

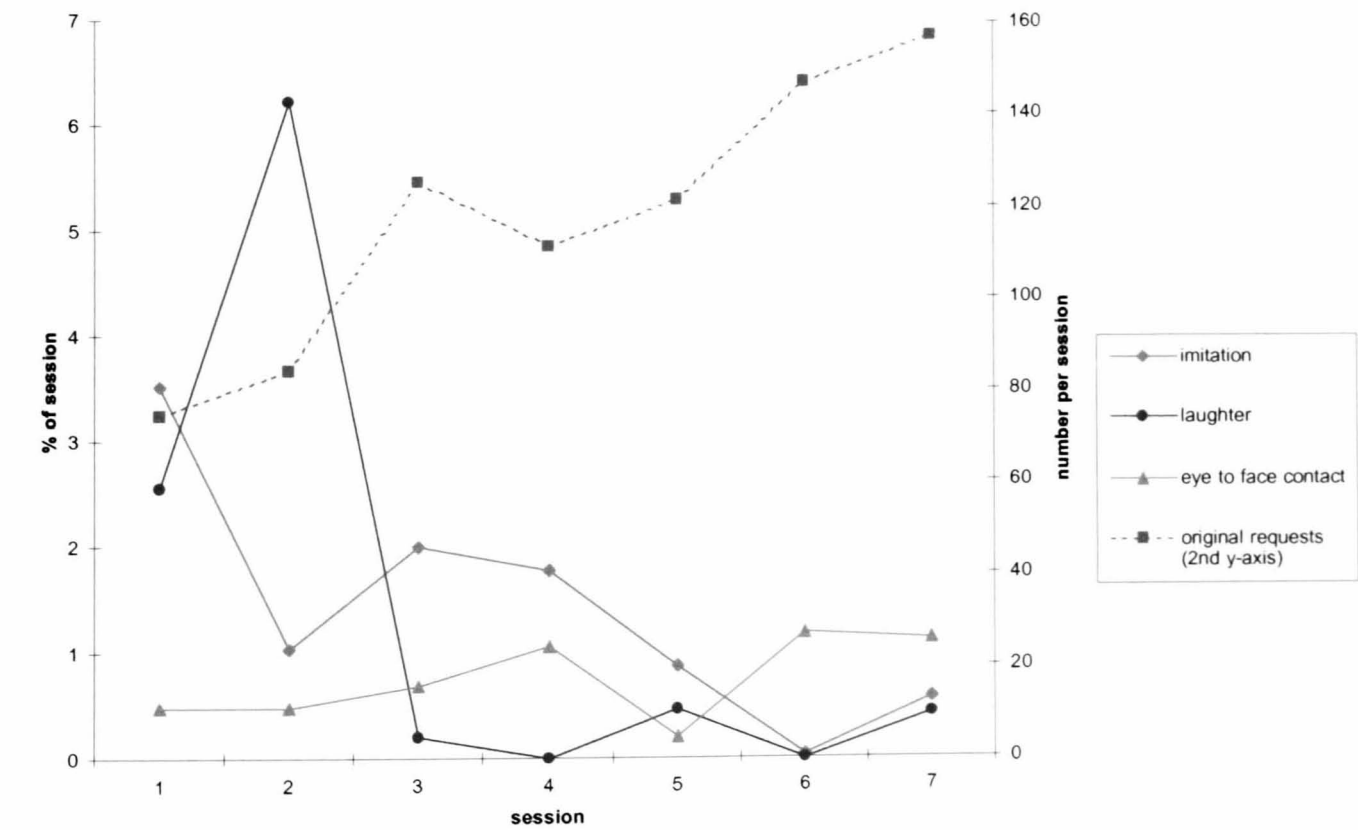


Figure F8: Pair I – relation between child’s behaviour and mother’s techniques

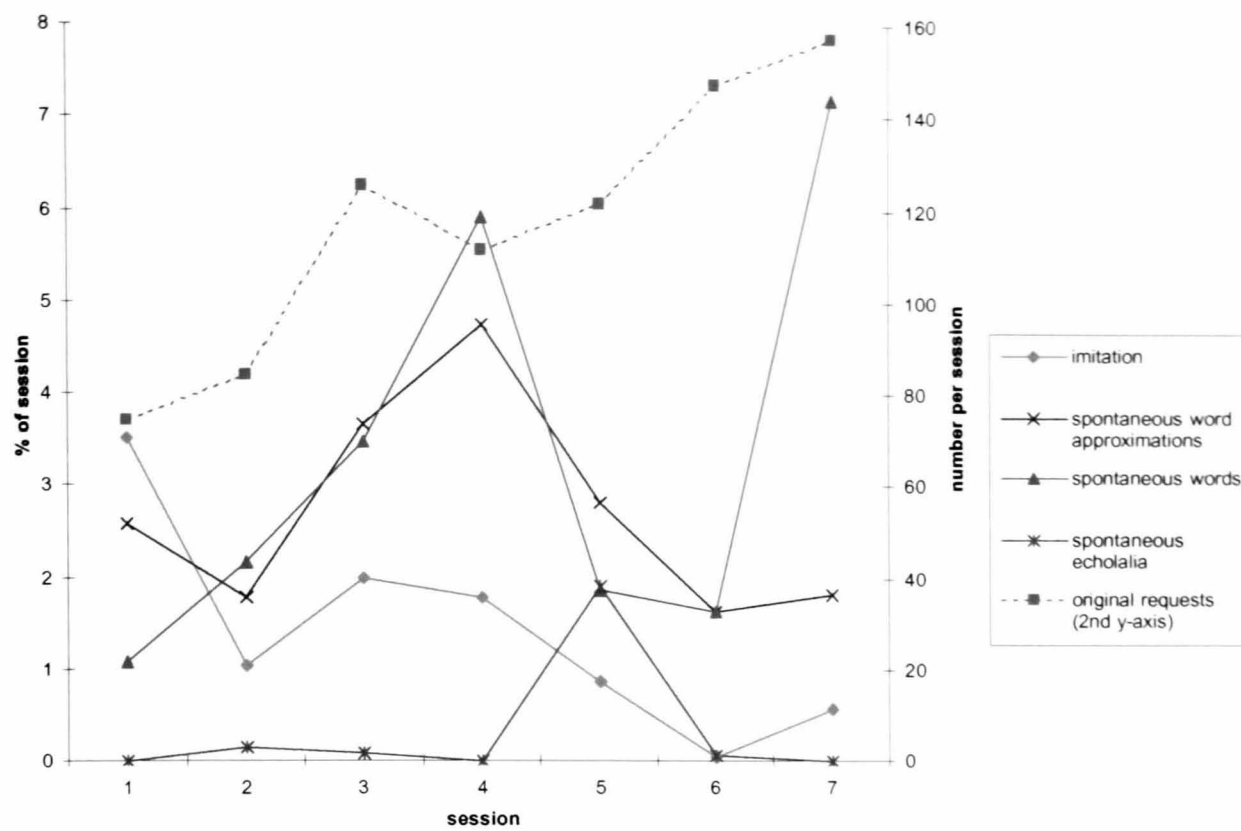


Figure F9: Pair I – relation between child's vocalisations and mother's techniques

## Pair J

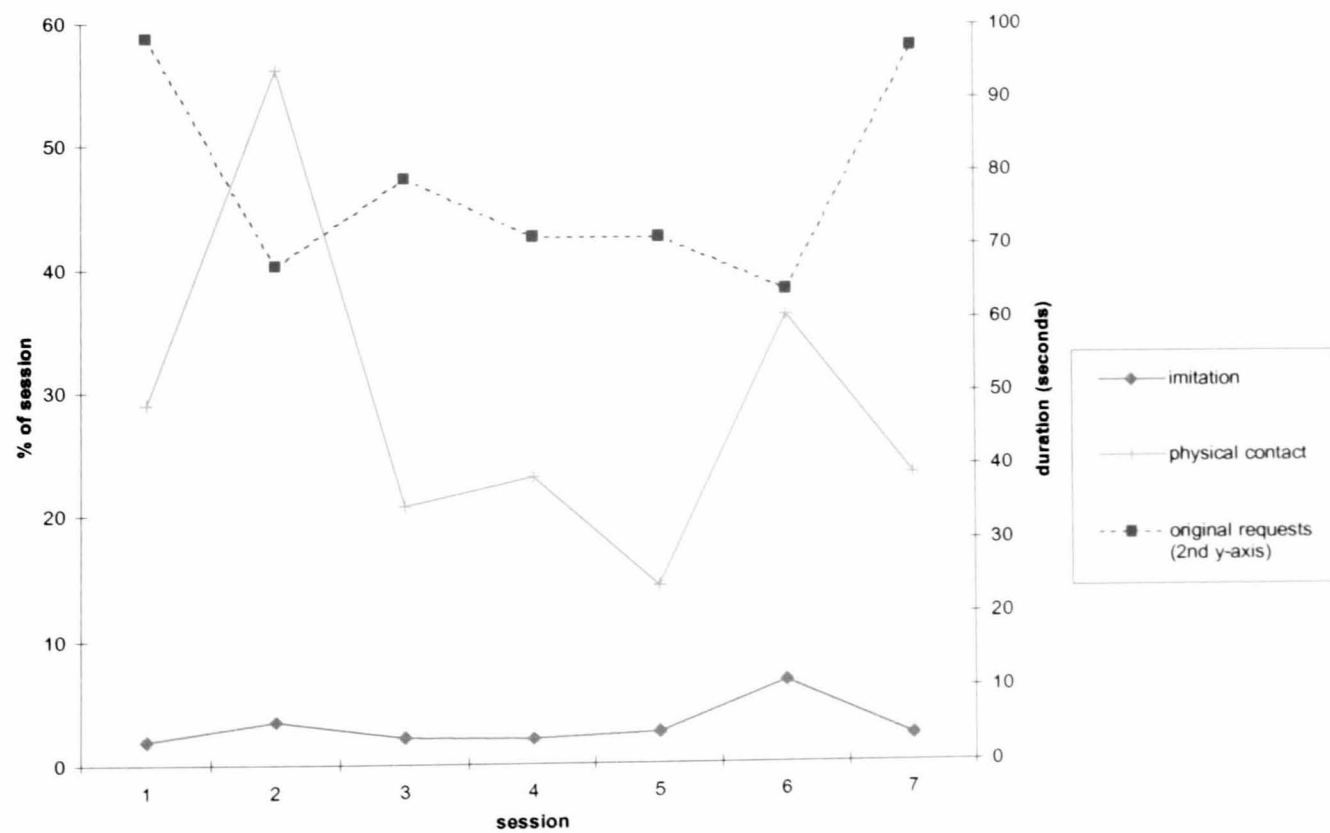


Figure F10: Pair J – relation between child's physical behaviour and mother's techniques

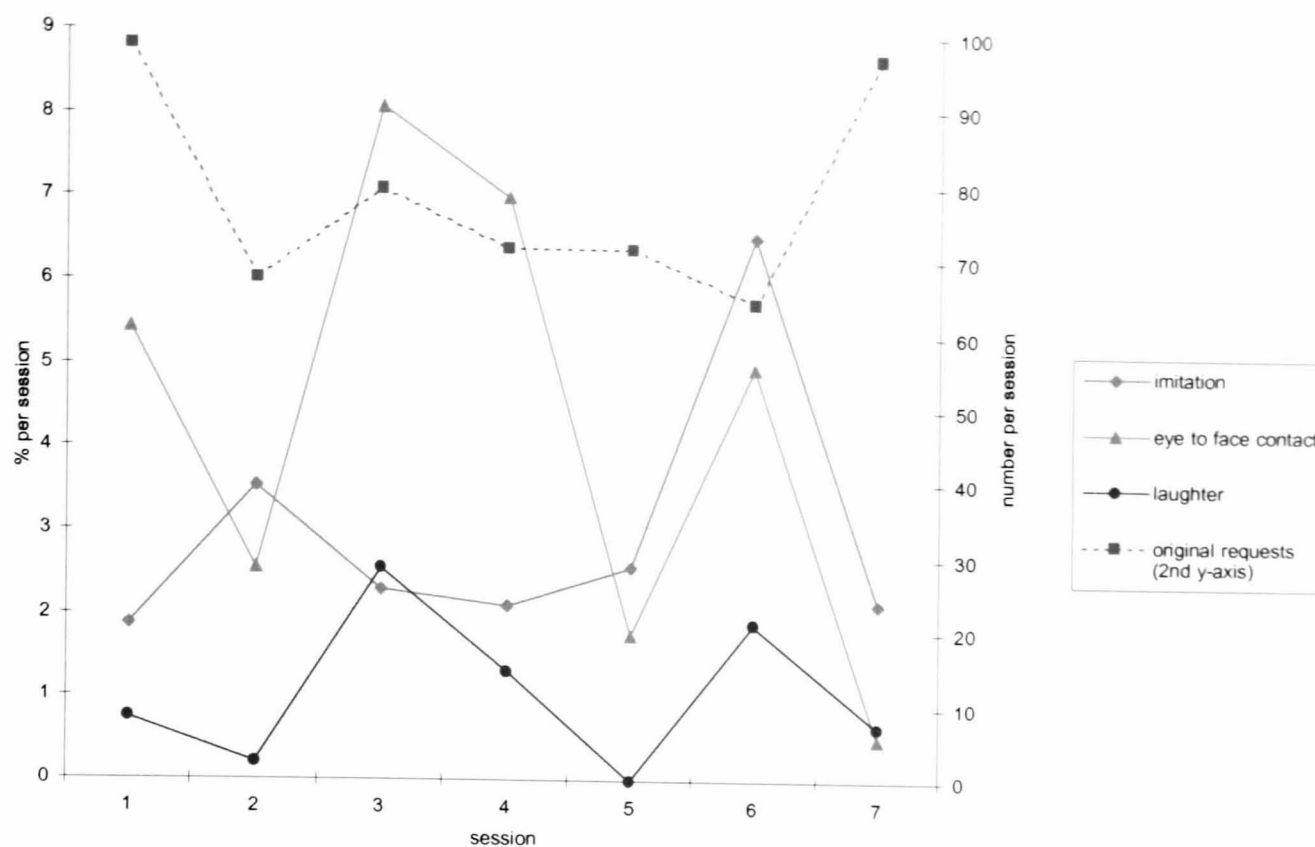


Figure F11: Pair J – relation between child's behaviour and mother's techniques

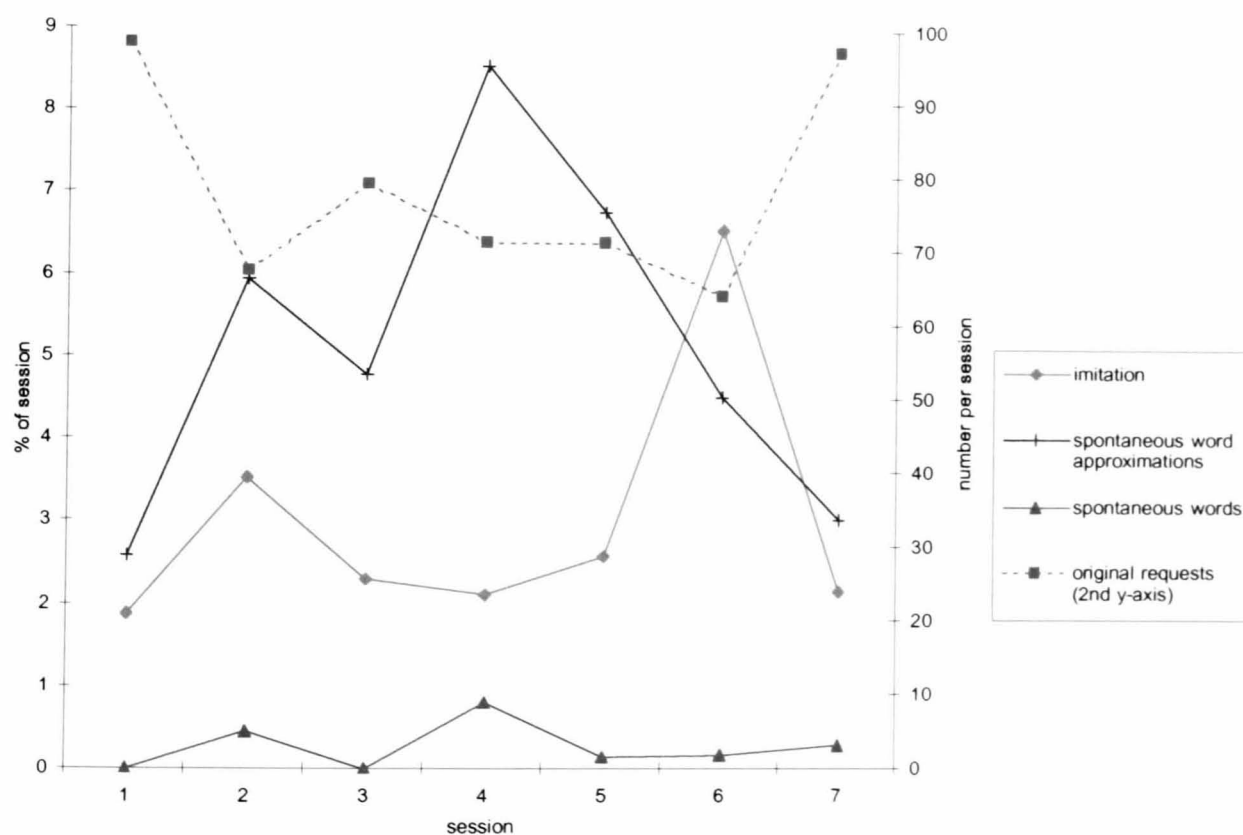


Figure F12: Pair J – relation between child's vocalisations and mother's techniques

Pair K

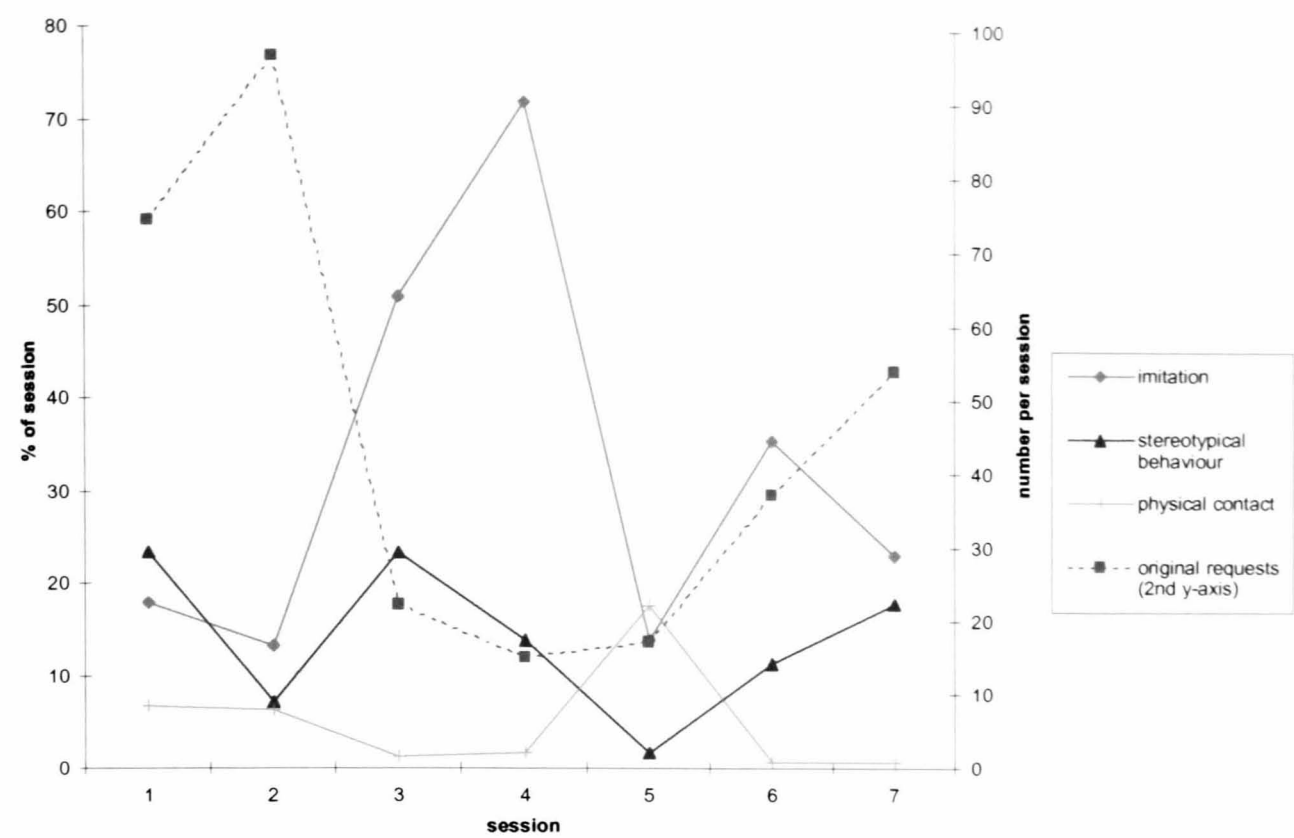


Figure F13: Pair K – relation between child’s physical behaviour and mother’s techniques

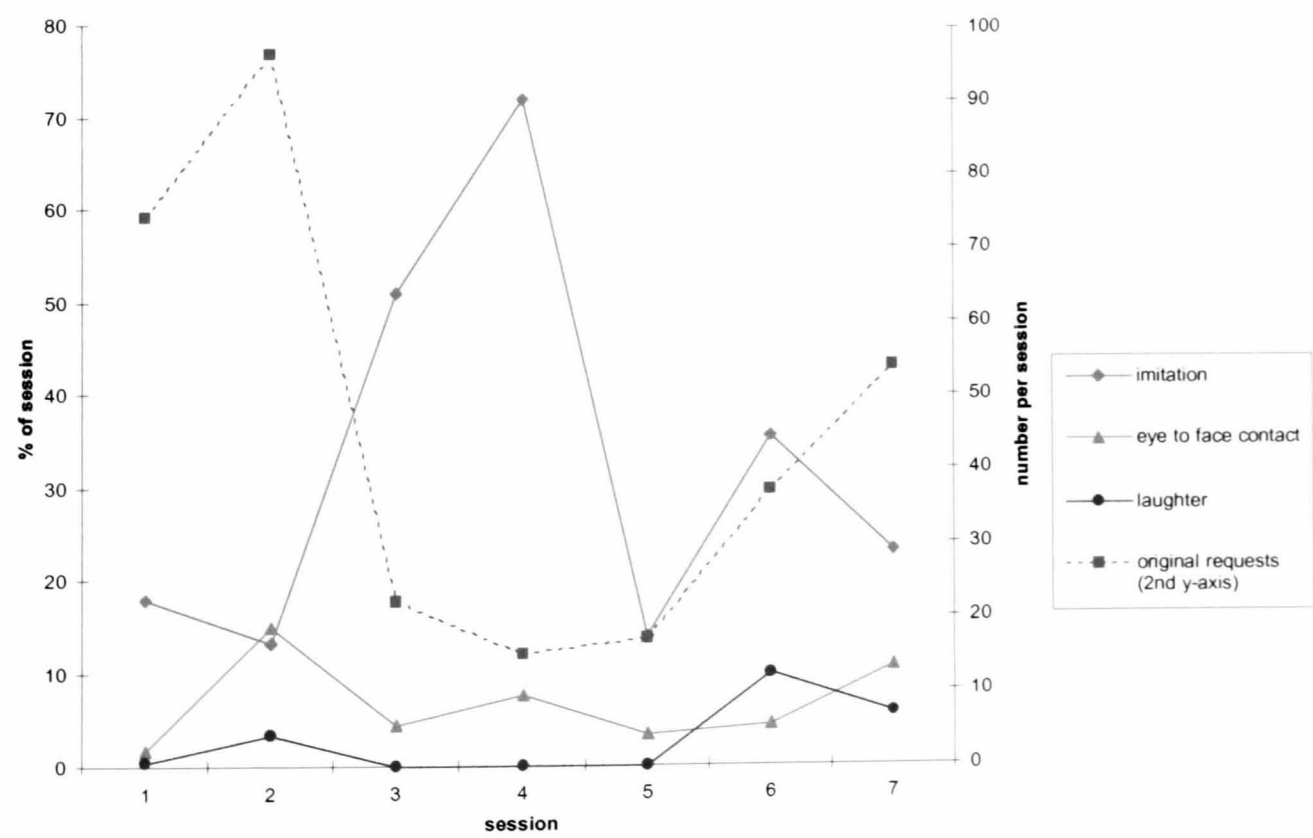


Figure F14: Pair K – relation between child’s behaviour and mother’s techniques



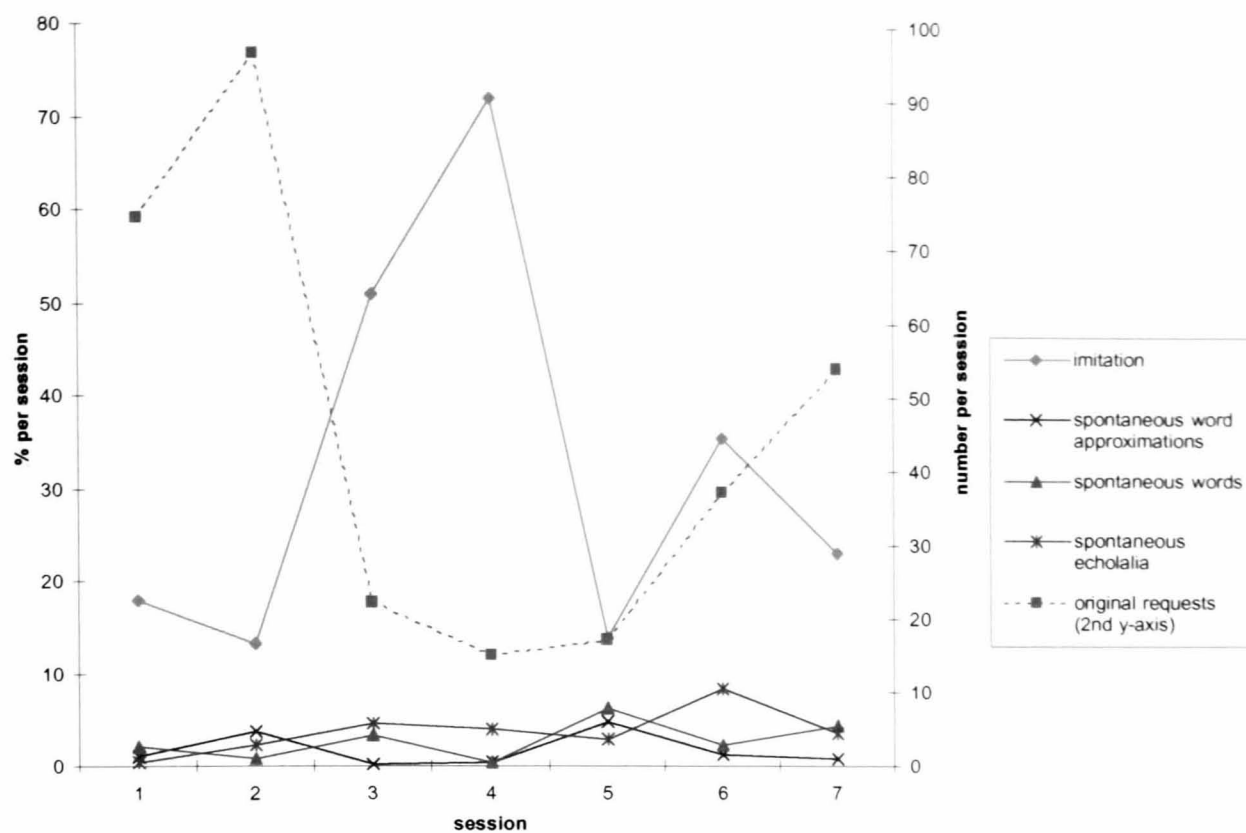


Figure F15: Pair K – relation between child's vocalisations and mother's techniques

## Pair L

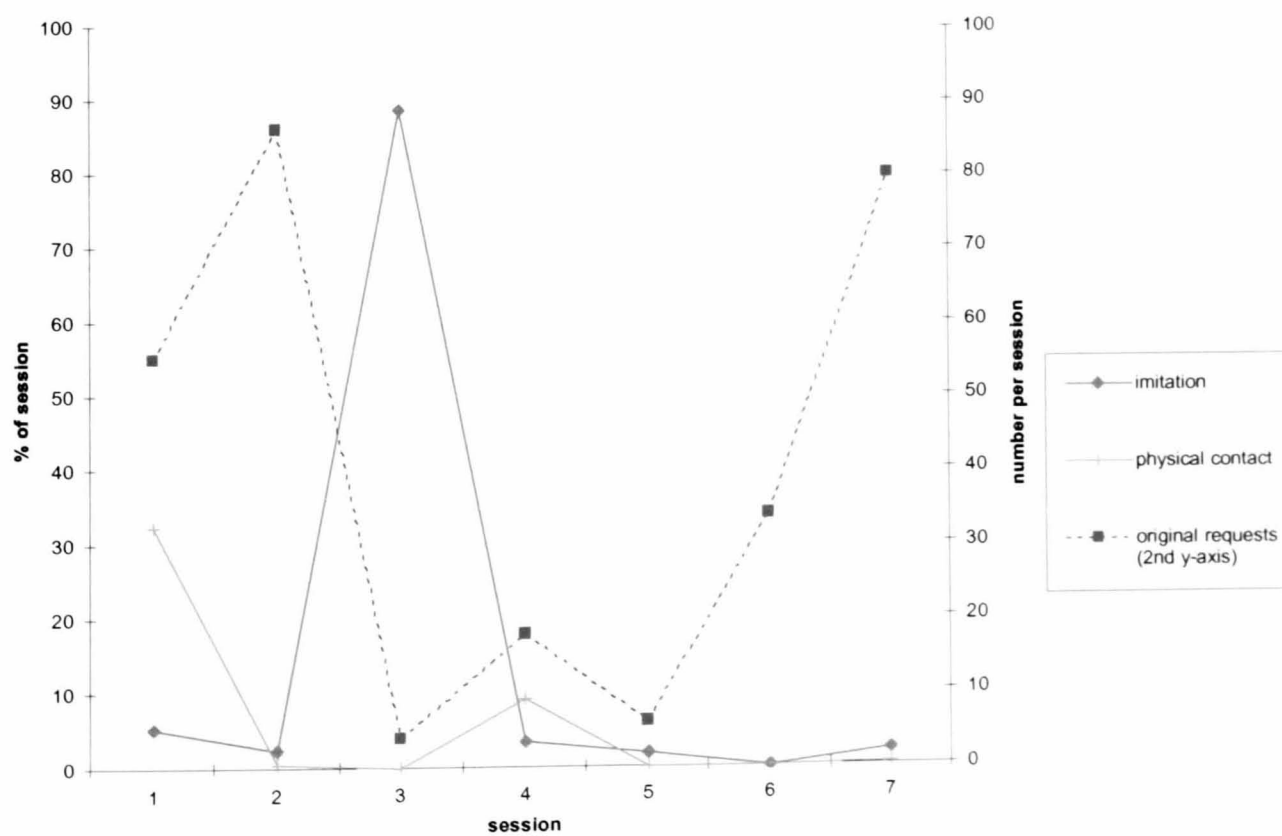


Figure F16: Pair L – relation between child's physical behaviour and mother's techniques

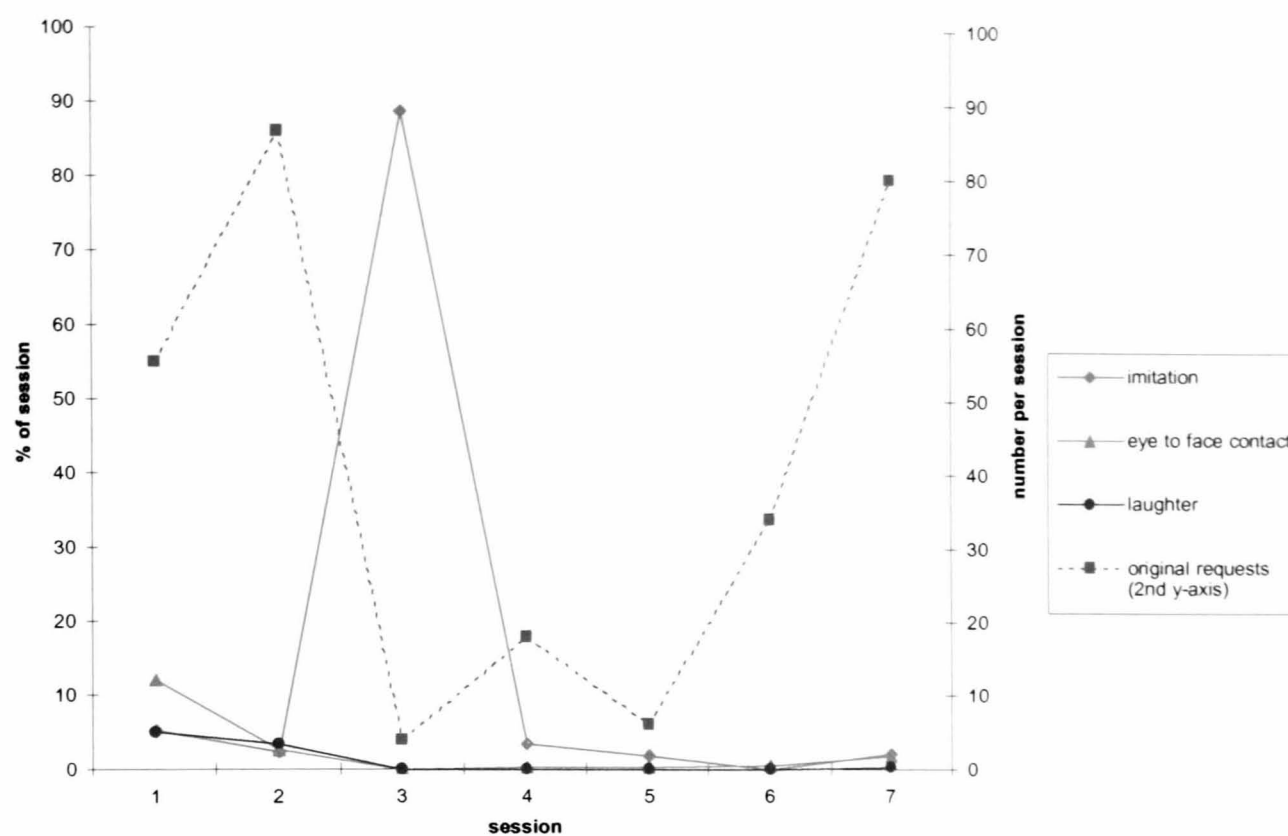


Figure F17: Pair L – relation between child's behaviour and mother's techniques

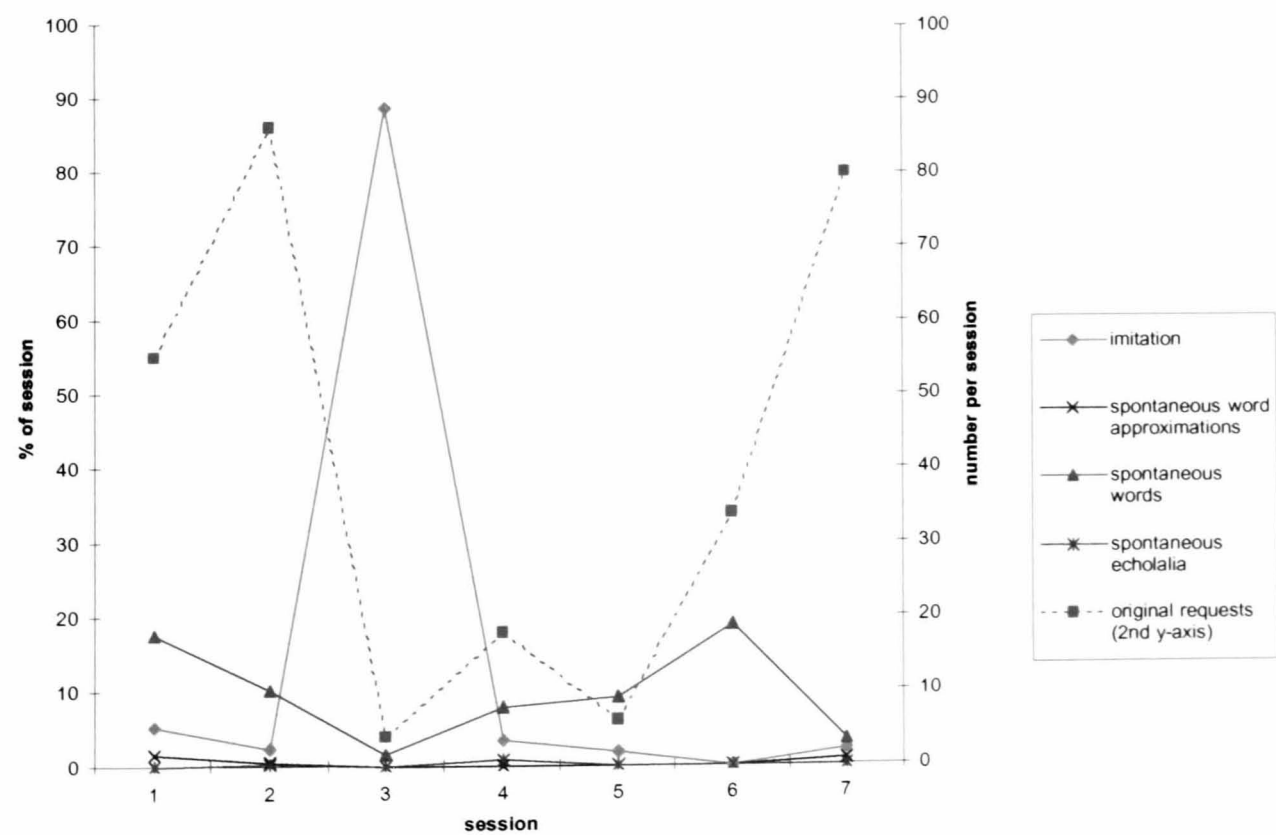


Figure F18: Pair L – relation between child's vocalisations and mother's techniques

## APPENDIX G

### PARENTS' IMPLEMENTATION OF THE SON-RISE PROGRAM: VIDEO REVIEW AND INTERVIEW SCHEDULE (STUDY 5)

#### Points to mention to parents immediately before the interview

As Appendix D

#### Instructions/Prompts for part 1 of interview

I'd like you to watch this tape, pausing it at any time you would like to make a comment (in addition tape will be paused at the end of each 5 min clip).

Can you remember...

#### *You*

- (1) Any particular techniques you felt that you were emphasising or not at that stage e.g. were you trying to be particularly accepting of your child, or particularly challenging them.
- (2) Any use of techniques you feel, looking back, you have since improved upon.
- (3) How you felt then.

#### *Your Child*

- (1) The stage you feel your child was at in the clip.
- (2) How your child reacted to your Son-Rise techniques at that stage.

#### Part 2

- (1) I'm going to mention some of the Son-Rise techniques. For each one could you say if you have or haven't changed in your use of it in the playroom over the past year.
  - (a) Joining in with child, e.g. imitating 'isms', joining in with repetitive activities, joining in with their choice of activity.
  - (b) Extending the child's activity - thinking of good ways and good moments to do this (e.g. requesting that the child does something).
  - (c) Acceptance of 'challenging behaviour.'
  - (d) Being present.
  - (e) Maintaining energy, excitement and enthusiasm.
  - (f) Using the idea that 'Happiness is a Choice.'
  - (g) Any other techniques you feel are important.

#### *Prompts*

Have there been changes or no changes in:

- (i) How much you use it
- (ii) Your ability to use it
- (iii) Your child's response to it.

- (2) How confident have you felt over the past year that you have been 'going in the right direction' with your child?

What I mean by that is how confident have you been that you have been choosing the correct goals to focus on, that you have been challenging your child enough but not too much etc.

- (3) What progress do you feel that your child has made over the past year, if any, in the following areas - none, some, a lot:
- (a) Language - comprehension, production, echolalia, and non-verbal communication.
  - (b) Social
  - (c) Toilet training
  - (d) Isms/repetitive behaviour
  - (e) Eye contact
  - (f) 'Academic Skills' e.g. reading, writing, number.
  - (g) Play skills
  - (h) Attention
  - (i) Challenging behaviour
  - (j) Other
- (4) For each of the areas above do you feel that your child progressed as much as you had expected them to in this area or not?
- (5) (a) To what extent would you attribute these changes to Options?  
(b) What else do you think has influenced change?
- (6) Do you think your expectations of what can be achieved through this approach have changed since the Start-Up course?
- (7) Do you feel that the number of hours you do with your child makes a difference to the amount of progress your child makes?  
*If yes - a little? A lot?*
- (8) Do you think that having volunteers affects or doesn't affect how you yourself work in the room?
- (9) Have you used phone calls/video feedback with the Options Institute? If so, how often, and to discuss what problems?
- (10) How well do you feel the Son-Rise Start-Up course and the Maximum Impact and back-up support prepared you for putting the techniques into practice?
- (11) Do you feel that you apply the attitudes and beliefs of the Option Process to the rest of your life (aside from interactions with your child) or not really?  
*Prompt*  
Tell me a bit more about that
- (12) Overall, how would you sum up your experiences of the Son-Rise Program over the past year?

# APPENDIX H

## PUBLICATIONS

### **Paper 1:**

Williams, K., & Wishart, J.G. (2001) Combining school attendance with home-based interventions for autism. *Journal of Research in Special Educational Needs*, 1(1). Available at <http://www.nasen.org.uk>

### **Paper 2:**

Williams, K., & Wishart, J. G. (1999) The Experience of Families Implementing the Son-Rise Program Intervention for Autism. In G. Linfoot & P. Shattock (Eds.), *From Research into Therapy* (pp. 91-102). Sunderland: Autism Research Unit, University of Sunderland.

## Paper 1

### Combining School Attendance With Home-based Interventions for Autism

Katie Williams and Jennifer G Wishart

#### Abstract

Despite the increased parental involvement in interventions for autism over recent decades, and the wide variety of home-based interventions which now exist, little is known about how these fit in with school attendance. Families' use of one intensive home-based intervention, the Son-Rise Program, was examined through a one-year longitudinal questionnaire and interview study. Issues relating to school attendance were examined, including parents' decision-making processes regarding concurrent school attendance, issues of compatibility between home and school, and issues arising for those families who discontinued school attendance in order to run a full-time intervention at home. Rather than using the Program exclusively and intensively, it was found that many families used the recommended intervention techniques part-time in the home whilst continuing their child's school attendance, and found the two learning contexts to be compatible with each other. Parents also identified a number of ways in which compatibility could be further maximised.

#### Introduction

Autism is a developmental disability which recent estimates suggest affects more than 500,000 people in the UK (National Autistic Society, 2000). It is often diagnosed during the child's preschool years, based on symptoms which form what Wing and Gould (1979) have described as a 'triad of impairments' in social interaction, communication, and flexibility of thinking and behaviour. Although the presentation of symptoms change as the child ages, it is a lifelong disability.

The benefits of early intervention for children with autism are well established, and since the 1960s there has been a move towards greater parent involvement in these programmes (Bristol et al., 1996; Howlin and Rutter, 1987; Lovaas et al., 1978). Despite the fact that there is now a wide variety of different interventions for autism used in the home by parents, there is still a lack of research into how these fit in with school attendance. There are insufficient data, for example, on how many parents tend to continue or discontinue school attendance when using home-based interventions. In addition, little is known about how parents and teachers can work together to maximise the effectiveness of an approach which combines home intervention with school. A further area of uncertainty concerns the issues which arise for families who discontinue school attendance to run a full-time intervention.

This paper reports on a study investigating the use of one such home-based therapy, the Son-Rise Program, also known in the UK as the Option approach (Kaufman, 1994). This is an American therapy, developed by the Kaufmans for children and adults with a variety of special educational needs, although the study to be reported here focuses only on the application of the Son-Rise Program with children on the autistic spectrum, the group with which this approach is most commonly used. The Son-Rise Program is run by parents, often with the help of a team of volunteers. Parents using the therapy turn one of the rooms in their home into a playroom, specifically designed to minimise distractions, and work in this with their child on a one-to-one

basis. There is no interaction with other children in a typical Son-Rise session. It is a child-led approach based on the fundamental principle that the attitude of the adult towards the child is accepting and non-judgemental at all times. The adult conveys this acceptance by joining in with the child's choice of activity and expanding on it with great enthusiasm and energy, the aim being to help the child to develop and become more interactive. The approach is used by some families on an intensive basis - for example the Kaufmans used it originally with their own son Raun for over 80 hours each week. Other families choose to use the method part-time in combination with school attendance.

There have been individual case studies published on the use of the Son-Rise Program, and a limited number of studies exploring the profile of children involved in the approach and the experience of families using it (Jordan, 1990; Kaufman, 1981; 1994; Williams and Wishart, 1999). However there is both a lack of substantive data on its effectiveness and a lack of documentation about the decisions made by parents regarding their child's school attendance when using Son-Rise.

This paper reports on a one-year questionnaire and interview-based study of parents using the Son-Rise Program with their children with autism. The study documented the experience of families using the Son-Rise Program and provided a profile of users and of patterns of use. It addressed a wide range of topics relating to the implementation of the Son-Rise Program. This paper will focus specifically on the issues relating to school attendance. In particular the following questions were explored:

- (1) What proportion of families using the Son-Rise Program:
  - discontinue school attendance?
  - continue with full-time school attendance?
  - continue with part-time school attendance?
- (2) What influences the parents' decision-making processes regarding school attendance?
- (3) Do parents feel that their child's schooling is compatible with the Son-Rise Program?
- (4) What steps can be taken to maximise this compatibility?
- (5) What are the issues that parents should consider before removing their child from school to run a full-time Son-Rise Program?

## Method

The questionnaire was initially sent to 134 parents and professionals who had participated in a one week Son-Rise Start-Up course. This is the initial training undertaken by parents wishing to set up a home-based Son-Rise Program. There were 85 returns to this initial approach, a response rate of 63%. These included replies from 76 parents who intended to begin a home-based Son-Rise Program, representing 77 children on the autistic spectrum. These parents were sent a second follow-up questionnaire six months later, and a final questionnaire one year after the initial Start-Up course.

The questionnaires requested demographic information such as the child's age and diagnosis, family composition, and whether the parents were employed. It also covered a large number of topics relating to intervention implementation, including hours of intervention provided for the child each week, parental confidence in using the intervention techniques, effects of involvement on the whole family, and decisions regarding school attendance.

Inevitably a questionnaire which covered so many aspects of intervention implementation was limited in the extent to which any one issue could be explored. For this reason an interlinked interview study was used to explore issues such as school attendance in greater depth.

Six parents from the questionnaire sample were selected for interview, using a ‘stratified purposeful’ sampling method (Cohen, Manion and Morrison, 2000). This meant that families were selected on the basis of being proportionately representative of the total population of families who had returned the first questionnaire in terms of:

- child’s diagnosis
- child’s age
- whether the child had siblings
- number of planned intervention hours per week
- whether the parents were employed
- parents’ current confidence level in interacting with their child using the Son-Rise Program.

These characteristics were selected on the basis of previous literature suggesting an association between these factors and intervention outcome for the child (Dawson and Osterling, 1997; Lovaas, 1987; Prizant and Rubin, 1999).

Table 1 shows a subset of the characteristics of the six families who participated in the interview study and illustrates the wide variety in the children’s ages and the planned hours of intervention across the sample. In terms of schooling, two of the families continued full-time attendance, two continued on a part-time basis and one family discontinued completely. Child F was between schools at the time of the first interview but was attending school on a full-time basis at a later stage in the study. Two of the children were of preschool age and the rest were school age.

**Table 1: Profile of the six interview families**

Family	A	B	C	D	E	F
child's name	Andrew	Billy	Colin	Daniel	Emma	Fergus
child's sex	M	M	M	M	F	M
child's age *	5 yrs	3 yrs	5 yrs	4 yrs	10 yrs	6 yrs
child's diagnosis	autism**	autistic tendencies	autistic tendencies, SLD,*** motor diffs	autism	autism, learning difficulties	autism**
planned hrs per week	1-10	21-30	21-30	11-20	31-40	41+
planned school attendance	continue full-time	continue part-time	continue part-time	continue full-time	discontinue	unsure
preschool/school	school	preschool	school	preschool	school	school

\* The ages of children given are their ages at the time of the first interview  
 \*\* At the time of this study it had not been established whether or not these children had associated learning difficulties  
 \*\*\* SLD = severe learning difficulties

The first round of interviews took place approximately two months after the Start-Up course. Following this the parents were interviewed again after Questionnaire 2 and Questionnaire 3 had been returned. Only one parent from each family was interviewed, and in all cases this was the mother, who was interviewed in the home. The interviews were semi-structured, covering in greater detail the topics explored in the questionnaire.



Results

Questionnaire data

The proportions of children who continued and discontinued school after beginning the Son-Rise Program were specifically examined in the second of the three questionnaires. Questionnaire 2 was sent to all of the parents of children with autism who had indicated in Questionnaire 1 that they intended to use a Son-Rise Program. 77 questionnaires were sent out and 61 were returned, a response rate of 79%. Of these, parents of 48 children had begun their home-based Son-Rise Program.

Of these 48 children, four were not attending school or preschool, nor had been prior to beginning Son-Rise, as the parents felt they were too young. Of the remaining 44 children, the majority continued to attend preschool/school on either a full- or part-time basis during their Son-Rise Program, as Table 2 shows. Families with children at school were equally likely to discontinue school attendance as families with children attending preschool.

Table 2: Children’s school attendance (Questionnaire 2)

School attendance	No. of children (%)	School	Preschool
Continue to attend full-time	24 (55%)	18	6
Continue to attend part-time	11 (25%)	6	5
Discontinue	9 (20%)	6	3

Overall 80% of children continued to attend school or preschool on either a full or part-time basis, a finding which was somewhat surprising. The popular image of Son-Rise Program parents is of parents who use the program exclusively and intensively, such as the 80 hours per week used by the Kaufmans (Kaufman, 1994). In contrast, the findings from this questionnaire suggest that the pattern in the UK is of less intensive use combined with school attendance.

So why do the majority of UK families choose to continue school attendance while using an intervention which has been typically described as a full-time approach? In Questionnaire 2 parents were asked for their reasons for continuing or discontinuing their child’s school attendance. This was an open-ended question and parents often gave several reasons.

The parents of 19 of the 24 children who continued school on a full-time basis and 8 of the 11 who continued on a part-time basis described their reasons for continuation, as shown in Table 3. The most common reason given was that they felt the school environment was beneficial for their child. Most often this was because of the enjoyment that school provided for the child, a factor mentioned by 12 parents. Ten mentioned the benefits of social interaction at school, and four felt that school was beneficial because of the skills their child learnt there. The benefits of school were summed up by one mother who said of her son:

*‘He seems really happy ... he just goes in “bye bye mummy”, and he comes home ... and he talks about swimming, he talks about going on the slide, going to Tesco. He talks about the children in his class ... and he’s getting the chance to interact with children, which I feel is quite good.’*

Only four parents continued their child's attendance because they felt it would be impossible to run a full-time Son-Rise Program because of work commitments or a lack of volunteers. As Table 3 shows, the majority chose to continue school attendance because they felt that school was a good environment for their child, not because they were unable to run a full-time program and had no option but to send their child to school.

**Table 3: Reasons for continuing attendance at school, or continuing on a part-time basis (Questionnaire 2)**

Reason	No. of times reported
Benefits of school	22
Two environments of school and Son-Rise compatible/beneficial or coped with by child	6
Child settled/can cope with school	5
Impossible to run a full-time Son-Rise Program	4
To avoid losing place at school	1
School supportive of Son-Rise Program	1
To allow time for self	1

The most common reason given by the parents of the nine children whose attendance was discontinued, as well as two of the eleven who continued part-time, for reducing or suspending school attendance was that they were dissatisfied with their child's school (see Table 4). In two cases this was because of the lack of one-to-one teaching, and in another two cases it was because their child was not encouraged to interact with other children.

**Table 4: Reasons for discontinuing school attendance or reducing hours at school (Questionnaire 2)**

Reason	No. of times reported
Dissatisfaction with school	7
Two environments potentially incompatible	3
Wish to run full-time Son-Rise Program	1
Due to progress made through Son-Rise Program	1
At teacher's request	1

Surprisingly then, it was found that the majority of children continued to attend school. Parents, on the whole, regarded school as a beneficial environment for their child and continued their child's attendance for positive reasons - because they chose to, not because they were unable to run a full-time program and had no alternative but to send their child to school.

#### Interview data

Decision-making on school attendance, issues of compatibility, and areas of concern for parents discontinuing school attendance were explored in greater depth in the six families participating in the interview part of the study (see Table 1). Of these families four initially used a combination of Son-Rise and school attendance, a feature which may have been expected to raise issues relating to the compatibility of the two approaches. Ozonoff and Cathcart (1998) have suggested that a combination of approaches may influence the effectiveness of any one method if the child receives conflicting messages from the different approaches. For example, behaviour that may be deemed acceptable within the Son-Rise Program may be seen as unacceptable and discouraged at school, leaving the child uncertain as to what constitutes appropriate behaviour. It is important

therefore to establish whether the two approaches are seen as working effectively in combination, and how their compatibility can be maximised.

In this study it was found that none of the interviewed families whose children were involved in both school and Son-Rise felt that their child was getting 'mixed messages' or was confused by experiencing both environments. This may be related to the fact that although parents thought that the approach taken in their child's school was, of necessity, not identical to the Son-Rise Program, they nevertheless felt that there were similarities. One mother commented:

*'They don't force him to do anything ... There's certain things that they all go to, like swimming, and they all go to lunch, but its not a regime. They don't sit there at the painting table and force him to paint. If he doesn't want to paint, he doesn't paint. So it's quite good in that respect, that it's not working against what we're doing.'*

Interestingly, it was the parents of the younger children who reported that their child's school had a similar child-led ethos to the Son-Rise Program. Mrs. E, whose daughter at ten years of age was the oldest child in the sample, felt that Emma's school was very accepting of its pupils, but did not mention a child-led approach to teaching. It may be that compatibility between school and Son-Rise is greater at younger ages, when the focus is more on social than academic development and there is less need to meet targets in the 5-14 curriculum.

During the interviews some ways in which the compatibility of school and the Son-Rise Program could be maximised were discussed. These included:

- parents sharing information on the Son-Rise techniques in order to allow optimal continuity of approach between school and home wherever possible

- a two-way sharing of information between school and home about developmental goals for the child. (This may be particularly helpful, as Jordan (1990) has suggested that parents involved in the Son-Rise Program may be uncertain of the developmental sequence that educational skills should be taught in.)
- an overlap of staff between the two settings (for example an auxiliary from school working as a volunteer in the Son-Rise Program)
- if the child is attending school on a part-time basis, teachers rearranging the timetable so it worked to the child's best advantage as far as possible. (For example, in the case of family C, the school rearranged Colin's timetable so that he could still have the swimming lessons they felt were important for development of his motor skills. They also made a point of letting Mrs. C know which lessons Colin was missing, so she could make up for this at home if need be.)

Mrs. E, who discontinued her child's school attendance, noted a number of issues which might be relevant for other families considering taking their child out of school. Firstly, the child may lose access to related services: Emma could no longer attend speech and language therapy or music therapy as these had previously been provided through the school. Mrs. E also felt that although a younger child could run around the Son-Rise playroom, Emma at ten years old required more in the way of exercise. Taking Emma out of school meant that she no longer had access to the school swimming pool and daily exercise classes, and Mrs. E found it difficult to provide her with such frequent opportunities for physical exercise.

Mrs. E arranged for Emma's special school place to be kept open during a three-month trial period of full-time Son-Rise. Such an arrangement is advisable as it provides continuity for the child if and when they do return to school; it also eases pressure on the parents by offering a 'safety net' if the Program does not work out as well as expected. In the case of family E, however, the school did not keep Emma's place open as expected, and it was only through the

intervention of her local MP that she got back into school. Mrs. E felt that this situation had placed a great deal of stress on the family and shaken their confidence in the educational authorities. She commented:

*'I was really very disappointed all round with the lack of support and the lack of concern for the child. It was merely a numbers game. It was almost political between our region and the region in which she goes to school. I could see that was going on, like "we've got this little bit of power." I was disgusted by that attitude.'*

## Discussion

It was found in this study that the majority of children continued to attend school while involved in a home-based Son-Rise Program. This suggests that if a much needed evaluation of the efficacy of Son-Rise does take place in the future, it would be advantageous for the intervention group to include children experiencing a combination Son-Rise/school approach. The evaluation would then reflect how the intervention is used by families in the 'real world', increasing the generalisability of the evaluation findings and ensuring that the study is relevant for families considering using the approach.

However, another implication is that the kind of combination approach taken by the majority of parents in this study will make it very difficult to attribute developmental change in the child specifically to the Son-Rise Program (Jordan, Jones and Murray, 1998; Prizant and Rubin, 1999). This may leave parents uncertain of whether the time, money and effort being put into their child's Son-Rise Program is truly worthwhile.

As hoped, the interview data provided much richer information on parental decision-making in relation to school attendance. Within the interview families it was found that conflicts resulting from different interaction styles in the two learning environments appeared to be minimal,

particularly in the case of the younger children. Although small numbers limit the generalisability of this finding, the data are consistent with previous research showing that simultaneous implementation of two treatment models will not necessarily be confusing for children (Ozonoff and Cathcart, 1998). The interview study also suggested that good communication and a degree of flexibility on the part of both the parents and the teachers can greatly aid the compatibility of the two environments.

Perhaps the most important point raised in this study is the need to keep the child's school place open for a trial period if a family decides to try a full-time home-based intervention. Jordan, Jones and Murray (1998) note that it is important for doors to be left open for return 'to the fold of LEA provision.' The stress suffered by family E when their daughter lost her place at school emphasises the need for contact to be maintained between parents and the relevant local authority.

The effectiveness of combining school and Son-Rise in terms of developmental progress in the child remains to be seen. This study does suggest, however, that at least in some cases the Son-Rise Program and school is a feasible combination for children with autism and one with which families feel comfortable.

The experience of families using the Son-Rise Program is being explored in greater depth, in ongoing studies. Issues such as changes in parents' implementation of Son-Rise techniques over time, and the effect on the whole family of the parents taking on the role of their child's therapist, are being explored both through further questionnaire and interview studies and by analysis of videotaped Son-Rise sessions of mother-child interactions over a one-year period (Williams, 2001 – in preparation). It is hoped that these studies, together with the data reported here will help in understanding the experience of being involved in the Son-Rise Program, not just for the child with autism but also for the child's parents and teachers.

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## References

- BRISTOL, M. M., COHEN, D. J., COSTELLO, E. J., DENCKLA, M., ECKBERG, T. J., KALLEN, R., KRAEMER, H. C., LORD, C., MAURER, R., MCILVANE, W. J., MINSHEW, N., SIGMAN, M., and SPENCE, M. A. (1996) State of the science in autism: report to the National Institutes of Health. *Journal of Autism and Developmental Disorders*, 26, 2, 121-154.
- COHEN, D. J., MANION, L., and MORRISON, K. (2000) *Research Methods in Education* (5<sup>th</sup> edition). London and New York: Routledge.
- DAWSON, G. and OSTERLING, J. (1997) Early intervention in autism. In Guralnick, M. J. (ed.) *The Effectiveness of Early Intervention*. Baltimore: Paul H. Brookes.
- HOWLIN, P. and RUTTER, M. (1987) *Treatment of Autistic Children*. Chichester: Wiley.
- JORDAN, R. (1990) *The Option Approach to Autism: Observer Project Report*. Hatfield: Hatfield Polytechnic.
- JORDAN, R., JONES, G., and MURRAY, D. (1998) *Educational Interventions for Children With Autism: A Literature Review of Recent and Current Research. Research Report RR77*. London: Department for Education and Employment.
- KAUFMAN, B. N. (1981) *A Miracle To Believe In*. New York: Fawcett Crest.
- KAUFMAN, B. N. (1994) *Son-Rise: The Miracle Continues*. Tiburon, CA: H.J. Kramer Inc.
- LOVAAS, O. I. (1978) Parents as therapists. In Rutter, M. and Schopler, E. (eds) *Autism: A Reappraisal of Concepts and Treatment* (pp. 369 - 378). New York: Plenum Press.
- LOVAAS, O. I. (1987) Behavioural treatment and normal educational and intellectual functioning in young autistic children. *Journal of Consulting and Clinical Psychology*, 55, 1, 3-9.
- NATIONAL AUTISTIC SOCIETY (2000) *Fact Sheet: Statistics - How Many People Have Autistic Spectrum Disorders* [website]. Available: [http://www.oneworld.org/autism\\_uk/](http://www.oneworld.org/autism_uk/)
- OZONOFF, S. and CATHCART, K. (1998) Effectiveness of a home program intervention for young children with autism. *Journal of Autism and Developmental Disorders*, 28, 1, 25-32.
- PRIZANT, B. and RUBIN, E. (1999) Contemporary issues in interventions for autism spectrum disorders: a commentary. *The Journal of the Association for Persons with Severe Handicaps*, 24, 3, 199-208.
- WILLIAMS, K. The Son-Rise Program Intervention For Autism: Issues For Parents and Professionals. Unpublished PhD thesis, The University of Edinburgh. (To be submitted June 2001).
- WILLIAMS, K. and WISHART, J.G. (1999) The Son-Rise Program intervention for autism: issues for parents and professionals. In Linfoot, G. and Shattock, P. (eds) *From Research into Therapy* (pp. 91-102). Sunderland: Autism Research Unit, University of Sunderland.
- WING, L. and GOULD, J. (1979) Severe impairments of social interaction and associated abnormalities in children: epidemiology and classification. *Journal of Autism and Developmental Disorders*, 9, 11-29.



## Paper 2

### The Experience of Families Implementing the Son-Rise Program Intervention for Autism

Katie Williams and Jennifer G Wishart

#### Introduction

This paper reports on a study investigating the use of a home-based therapy, the Son-Rise Program, also known in the UK as the Option approach. It was developed for children and adults with a variety of special educational needs, although the study to be reported here focuses only on the application of the Son-Rise Program with children on the autistic spectrum, the group with which this approach is most commonly used. The Son-Rise Program is run by parents, often with the help of a team of volunteers, and is used by some families on an intensive basis. Parents using the therapy turn one of the rooms in their home into a playroom specifically designed to minimise distractions, and work in this with their child on a 1:1 basis. There is no interaction with other children in a typical Options session. It's a child-led approach based on the fundamental principle that the attitude of the adult towards the child is accepting and non-judgemental at all times. The adult conveys this acceptance by joining in with the child's choice of activity and expanding on it with great enthusiasm and energy, the aim being to help the child to develop and become more interactive.

There have been a small number of individual case studies published on the use of the Son-Rise Program (e.g. Kaufman 1981, 1994). However there is both a lack of wider data on its effectiveness and a lack of guidance on the kinds of children and families with which the program works best. It has also been noted that the Option Institute, which trains parents to use this approach, present only the positive aspects of being involved to families considering using it (Maurice, 1993). In addition, Jordan (1990) has suggested that UK parents considering using the Son-Rise Program should be given background information about it, but there is still a real lack of documentation about what exactly is involved for the whole family in its use.

This paper reports on a one year questionnaire-based study of parents using the Son-Rise Program with their children with autism. It seeks to explore the demographics of who is involved in this therapy as well as to provide an account of the experience of families using the approach.

A total of 135 questionnaires were initially sent out to participants of a Son-Rise 'Start-Up' course in London in 1998. This was a 5 day course offering initial training in how to implement a Son-Rise Program, attended primarily by parents, but also by a small number of professionals. Families with two children on the autistic spectrum were asked to fill in an additional questionnaire for their second child.

A second questionnaire was sent out six months later to those who had returned the first one, and a final questionnaire will be sent out at twelve months. This paper reports on findings from the first questionnaire in this study, as well as preliminary findings from the second.

Some of the questions being explored through this questionnaire study are:

- Who uses the Son-Rise Program?
- Why were they attracted to it?
- How do parents implement this approach to suit their own child and family circumstances?
- Do parents intend to continue their child's school attendance or discontinue it, in order to run a full-time Son-Rise Program?
- How do families feel about their use of the Son-Rise techniques and their running of the Program?
- Which issues arise for the whole family during implementation of this program?
- What progress do parents feel their children make with this approach?

### **Findings from questionnaire one**

Of the 135 questionnaires sent out 85 were returned (63%). Questionnaires returned came from predominately parents with children on the autistic spectrum, although there were 3 from professionals and 3 from parents of children with developmental disorders other than autism. Presented here are some of the findings from the parent replies - from the 76 families (representing 77 children on the autistic spectrum) who indicated that they intended to use the Son-Rise Program; only 2 families indicated that they did not intend to begin a Son-Rise Program, and these respondents will not be included in this particular analysis. At the time of questionnaire one most parents had not yet begun a Son-Rise Program and many of the questions therefore requested basic demographic details and information on parental intentions in relation to the use of the program at home.

#### *Who uses the Son-Rise Program?*

As can be seen from table 1, it is clear that a large proportion of children involved in this therapy are pre-school age. Parents with this age of child may be more likely to use a Son-Rise Program because of the belief that this type of intensive therapy is more likely to be successful with younger children, and also because published case studies have tended to focus on successful uses of the method with younger children (Kaufman 1981, 1994). It may also be related to the fact that the logistics of removing an older child from school to work with them at home are not always straight forward. Alternatively it may represent a difficulty in finding appropriate pre-school placements, leading to parents seeking alternatives. Jordan and Jones (1996), for example have described the inadequacy of preschool provision for children on the autistic spectrum in some parts of the country.

**Table 1 : Demographic information on those using the Son-Rise Program**

%	Child's diagnosis
61	autism
28	autistic tendencies/features
3	Asperger's syndrome
8	awaiting diagnosis
%	Time since diagnosis
8	awaiting diagnosis
46	within last 0;0 - 1;11 years
22	within last 2;0 - 3;11 years
23	4 + years ago
1	Not specified
%	Child's age
50	2;0 - 4;11 years
32	5;0 - 7;11 years
18	8 + years
%	Child's sex
74	male
26	female
%	Parents' employment
9	both full-time
26	one full-time, one part-time
59	one full-time, one not employed
4	neither employed
1	single parent full-time
1	single parent, not employed.

*Why do families choose the Son-Rise Program?*

Parents were asked what initially attracted them to this approach. This was an open-ended question and most parents gave several reasons. (table 2)

**Table 2: Reasons for choosing the Son-Rise Program**

<b>What attracted you to this approach?</b>	<b>No. respondents stating reason</b>
Aspects of the approach	46
Belief it has shown positive results with other families	18
Approach suits child/family	16
Believe it will help child progress	15
Offers hope to parents	12
Offers empowerment to parents	8
Lack of viable alternative	8
Other	17

Aspects of the Son-Rise Program itself was the factor which most often attracted families to it. Most commonly it was the attitude it embodies rather than specific techniques which appealed.

It causes concern that parents choose this approach because they believe it has shown positive results in the past. Reading of or witnessing positive outcomes in another family can be very motivating, and certainly it makes more sense to embark upon an approach which you believe has worked with other families, as opposed to one for which you have no evidence at all of effectiveness. However, despite anecdotal reports there has been no direct empirical evidence of significant measurable progress using this method, and while parents may see progress in the children of other families it may well be the case that what works for one child will not work for another. There is also the possibility that progress seen in children of other families is unrelated, or only partially related, to the Son-Rise Program.

The fact that belief in efficacy was a reason for parents choosing the approach emphasises the need for the Son-Rise Program to be evaluated, and for research to be conducted into which children this approach is most appropriate for.

*How do families implement this program to suit their own child and family circumstances?*

The questionnaire also looked at how many hours each week parents intended to use the program with their child. The minimum was 2, the maximum 84 and the average was 28.4. It is clear therefore that there is great variation between families in their implementation of this approach and this would need to be taken into account in any evaluation of its efficacy.

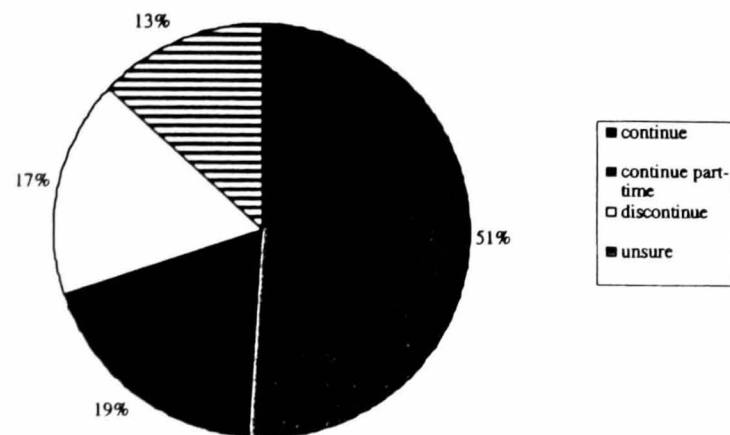
Parents were also asked whether they planned to use any other interventions at the same time as their Son-Rise Program. Jordan, Jones and Murray (1998) note that one of the difficulties when trying to evaluate the effectiveness of any intervention by measuring change in children with autism is that parents may try more than one approach simultaneously. This certainly seems to be the case here, with 69% of families planning to use at least one other intervention concurrently. This would make it difficult to attribute any change in the children solely to the Son-Rise Program, particularly if several therapies began at the same time. Aside from diet, the most common therapies that parents planned to use alongside the Son-Rise Program were speech therapy and the TEACCH approach. This suggests that research may also be needed to examine how the Son-Rise Program can most effectively be used in combination with these other interventions.

*Do parents intend to continue their child's school attendance or discontinue it, in order to run a full-time Son-Rise Program?*

For the 69 children who currently attended preschool/school, parents of the majority (70%) indicated that their child would continue at school, either full or part-time after beginning the Son-Rise Program (Fig 1).



Figure 1: Parental decisions on preschool/school attendance



The parents of only 12 children (17%) intended to discontinue their school attendance. Jordan (1990) reports that some of the Option staff feel that a Son-Rise Program may be less effective if the child is in two environments in which they might get conflicting messages, as may arise in relation to experiences in the Son-Rise playroom and school setting. However, since the majority of children will continue to attend school it is clear that there needs to be further examination of how schooling and the Son-Rise Program can work effectively concurrently, and how the child copes with any conflict in interactive styles.

#### *How do parents feel about using the Son-Rise techniques and running the Program?*

It would seem that the initial training course is effective in helping parents feel confident about their abilities to use a Son-Rise Program with their child (table 3). Howlin (1997) notes that giving parents such faith in their ability to help their child should not be underestimated, although it is important to avoid raising false hopes or setting unrealistic goals.

Table 3: Parents' confidence in using the Son-Rise Program

%	Parents' confidence in their ability to interact with their child using the Son-Rise Program
44	Very confident
38	Confident
16	Neutral
1	Not confident
1	Not at all confident
<b>Most confident about:</b>	
Joining in with the child's choice of activity	
Choosing to accept the child's behaviour	
<b>Need more training in:</b>	
Being creative in building on the activity	
Maintaining energy, excitement and enthusiasm	
%	Confidence in organising and running the Program
8	Very confident
35	Confident
34	Neutral
16	Not confident
3	Not at all confident
4	Not specified

At this stage parents were somewhat less confident about actually running the program (e.g. training volunteers, holding team meetings) than they were about interacting with their child using the techniques. However, it should be remembered that this questionnaire was sent out at a stage where most parents had not yet begun their Son-Rise Program, and a number of parents commented that they wanted to gain confidence in using the techniques themselves before they would feel confident about training volunteers.

## **Findings from Questionnaire 2**

Questionnaire 2 was sent out 6 months after the initial training course. Data collection is currently in progress and so analysis is still at a preliminary stage. The findings are presented here to give an indication of the trends which might be expected in the final analysis.

So far 41 of the 76 parents who indicated in questionnaire one that they intended to use the Son-Rise Program have returned the questionnaire. From these, only the results of 33 parents, representing 34 children, who have begun their home-based Son-Rise Program will be discussed.

### *Schooling*

To expand on the findings of the first questionnaire regarding parents' intentions about their child's schooling, a further question asking parents about their reasons for continuing or discontinuing their child's attendance at school was included. This was an open-ended question and parents sometimes gave a number of reasons for their decision.

Of those parents who decided to continue their child's school attendance, or continue it on a part-time basis as opposed to discontinuing it completely, the main reason given for this was that they felt that their child benefited from school. These benefits included social interaction with other children, learning academic and self-help skills, and in a number of cases, the enjoyment it provided for the child.

Other reasons for continuing included:

- parents felt that the school had an ethos and way of teaching which was compatible with the Son-Rise Program.
- parents felt unable to run a full-time Son-Rise Program, often because of work commitments.
- parents felt that their child was able to cope with the two different environments.

Of those parents who decided to discontinue their child's attendance, or reduce the number of hours their child spent at school, the main reason given was that they were dissatisfied in some way with the child's previous school and felt that their child was better off at home. Reasons for dissatisfaction included lack of 1:1 time at school and lack of progress by the child in that environment.

The next most common reason for parents discontinuing their child's school attendance was that they felt that the Son-Rise Program and the school environment were not compatible.

### *Effects on the Family*

Parents were asked whether running the Son-Rise Program had had any effects on the rest of the family. Some parents reported both benefits and drawbacks. At this stage of data collection positive changes have been mentioned by 13 of the 34 parents currently running a Program. These included the fact that learning about the accepting and positive attitude of the Son-Rise Program helped the interactions among other family members as well as with the child with autism.

Negative effects have been reported by 19 of the 34 parents, the main drawback being that parents had less time to spend with their spouse and other children.

Howlin (1996) notes that any benefits to the child of intensive programs must be weighed against disruption to normal family life and relationships. Although these findings show that implementing the Son-Rise Program does cause some disruption to family life it should be noted that several parents mentioned that this disruption was more than compensated for by the benefits, and that they did not regret beginning the Son-Rise Program.

Effects on family life will be examined again in the third questionnaire because several families indicated that they expected effects on the family to change over time. Many families, for example, were currently in the process of building up their number of volunteers, and they felt that when they had recruited more volunteers they would be able to spend more time with their other children, rendering negative effects transitory.

### *Child's Progress*

Questionnaire 2 also investigated the children's progress, as perceived by the parents. Respondents were asked about which areas, if any, they felt their child had progressed in. Increase in frequency and/or duration of eye contact was the most common area of progress noted, followed by social interaction and language.

Parents were then asked whether there were areas in which their child's progress was less than they would have hoped for. Several parents noted that it was too soon to comment, or that progress had in fact been greater than they had anticipated. However, the most common area of development where progress was less than anticipated was language.

There are several reasons why this might be the case. Firstly, it may be a reflection of the stage that parents are at with their Son-Rise Program. Many have begun to implement their program relatively recently, and therefore may be at a stage where they are concentrating on emphasising the accepting and non-judgemental attitude. Perhaps in later months they will move onto challenging their child more in the area of language use.

Secondly, progress in language may be less than anticipated because, as it currently stands, the Son-Rise Program may be more effective, for some children at least, in developing eye contact and social interaction than spoken language (Lynch, 1996).

Another possibility is that because language is made up of so many components parents may find it difficult to teach to their child because they are uncertain of the developmental sequence it should be taught in, an uncertainty which may also affect progress in other developmental areas (Jordan, 1990).

It should be re-emphasised that these findings represent only a preliminary analysis from the second questionnaire, and it remains to be seen whether these trends are confirmed when data collection is complete.

### **Discussion**

It is clear that an evaluation of the Son-Rise approach is much needed and it is hoped that the information reported here, in conjunction with follow-up information from questionnaires 3, will be of help with such a future study

Literature on home-based therapies for autism suggests that research is needed to establish the implications for the whole family of being involved in such therapies. The findings from this study show that while there are benefits to being involved in the Son-Rise Program, there are also areas of concern for some families.

However, the findings from Questionnaire 2 emphasise the importance of studying the changes in effects on the family, and in feelings about the approach, over time. The third questionnaire, to be sent out 12 months after the initial training course, will investigate this, as well as looking at decisions about schooling, and thoughts on the child's progress.

Other parts of the research programme, including interviews of a sample of parents from the questionnaire study, and video-analysis work monitoring implementation of the techniques, should also help in understanding the experience of being involved in the Son-Rise Program - not just for the child with autism but for the family as a whole.

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## References

- Howlin, P. (1996) Some approaches to modifying problem behaviours in autism. In G. Forrest & P. Vostanis (Eds.) ACPP Occasional Papers no. 13 Advances in the Assessment and Management of Autism. pp31 - 39, London: Association of Child Psychology & Psychiatry.
- Howlin, P. (1997b) Prognosis in autism: Do specialist treatments affect long-term outcome? *European Child and Adolescent Psychiatry*, 6, 55-72.
- Jordan, R. (1990) The Option Approach to Autism: Observer Project Report. London: National Autistic Society.
- Jordan, R. & Jones, G. (1996) Educational Provision For Children with Autism in Scotland. Edinburgh, SOEID.
- Jordan, R., Jones, G., & Murray, D. (1998) Educational Interventions for Children with Autism: A Literature Review of Recent and Current Research. Norwich: Department for Education and Employment Research Report no. 77
- Kaufman, B.N. (1981) A Miracle to Believe In. New York. Fawcett Crest
- Kaufman, B.N. (1994) Son-Rise : The Miracle Continues. Tiburon CA: HJ Kramer Inc.
- Lynch, S. (1996) Intensive behavioural intervention with a seven year old girl with autism. In G. Linfoot and P. Shattock (Eds.) Therapeutic Intervention in Autism. pp343 - 359, Autism Research Unit, University of Sunderland: National Autistic Society.
- Maurice, C. (1993) Let Me Hear Your Voice: A Family's triumph Over Autism. London: Robert Hale.